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100TH CONGRESS
2d Session

HOUSE OF REPRESENTATIVES

REPORT
100-588

A GENERATION IN JEOPARDY: CHILDREN AND AIDS

A REPORT

OF THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

U.S. HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

SECOND SESSION

together with

ADDITIONAL VIEWS

and

DISSENTING MINORITY VIEWS

APRIL 27, 1988.—Pursuant to section 206 of H. Res. 12, referred to the Committees on Energy and Commerce and Education and Labor and ordered to be printed

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U.S. HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES,
Washington, DC, April 26, 1988.

Hon. JIM WRIGHT,
The Speaker, U.S. House of Representatives, Washington, DC.

DEAR MR. SPEAKER: The Committee on Children, Youth, and Families is pleased to transmit the enclosed report entitled "A Generation in Jeopardy: Children and AIDS."

The report, which is being filed in accordance with Title II, Section 206.(a) of H. Res. 26, examines what is known about AIDS among infants, young children, and adolescents. It analyzes the implication for educational, medical and social services systems, identifies legal and ethical considerations, and reviews the federal response.

Respectfully submitted.

Sincerely,

GEORGE MILLER, *Chairman.*

Enclosure.

A GENERATION IN JEOPARDY: CHILDREN AND AIDS

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100TH CONGRESS
2d Session | HOUSE OF REPRESENTATIVES | REPORT
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A GENERATION IN JEOPARDY:

CHILDREN AND AIDS

APRIL 27, 1988.—Pursuant to section 206 of H. Res. 12, referred to the Committees on Energy and Commerce and Education and Labor and ordered to be printed

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Mr. MILLER of California, from the Select Committee on Children, Youth, and Families, submitted the following

REPORT

Introduction

AIDS (Acquired Immune Deficiency Syndrome) has rapidly become the Nation's number one public health threat. It has already taken the lives of more than 26,000 Americans, principally adults, and has devastated thousands more.

But AIDS is not limited to adults. It has already killed hundreds of children and threatens to kill thousands more, many of them very young.

As a nation we have failed to meet this terrible challenge, which only promises to worsen.

While the numbers of children who have AIDS and the AIDS virus remain low, they are increasing geometrically; consequently, the threat must be taken seriously.

To help understand the complexities of AIDS and its impact on children and teenagers, the Select Committee on Children,

Youth, and Families has conducted several hearings and culled the most up-to-date research and information. We have compiled and examined expert testimony, evolving knowledge, and emerging implications for our medical, educational and social services systems.

This report presents what we know about the threat of AIDS to infants, young children and teenagers, and how we can prevent its escalating toll. We recognize the limitations of any study, given the rapid advances in our knowledge and understanding of AIDS and its implications. We also recognize that every opportunity taken to focus attention on these issues may save lives.

Increasingly, those with the least access to information and fewest available resources -- low-income minority women and children -- are facing the greatest risk. We know that adolescents are especially vulnerable, because they are prone to engage in high risk behaviors that can lead to AIDS infection.

There is as yet no cure, vaccine or satisfactory treatment for AIDS. But it <u>can</u> be prevented. Individuals can protect themselves and reduce the risk of infection.

Surgeon General C. Everett Koop, the chief public health officer of the Nation, has stated that abstinence provides the only certain way to prevent the spread of AIDS through sexual contact. We agree. But, as Dr. Koop has emphasized, "because about 70% of adolescents are sexually active...if they haven't listened to the message of abstinence or monogamous relationships on a long-term basis, you have to introduce such things as condoms."

In the face of this epidemic, we must put aside ideology and marshall every available educational, medical and social service tool to address the AIDS epidemic.

If we fail to act now to limit the widening spread of AIDS, the public health threat of the 80's will become the public health and economic disaster of the 90's. Thousands of children will be lost; their families devastated. And the nation will be left reeling from the staggering and uncontrollable costs in lives and money.

We hope this report will serve to underscore the potential threat to children and youth, to fuel greater efforts to prevent the spread of AIDS and to improve care for those already infected by this deadly disease.

George Miller, Chairman
William Lehman
Patricia Schroeder
Lindy (Mrs. Hale) Boggs
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FINDINGS

INFANTS AND YOUNG CHILDREN

AIDS RAPIDLY EMERGING AS MAJOR HEALTH THREAT TO LARGE NUMBERS OF INFANTS AND YOUNG CHILDREN

* While still a small proportion of the total AIDS population, the cases of AIDS among children under 13 increased over 60% (from 420 to 691) from January 1987 - November 1987.

* Experts estimate that for every child with active AIDS, several others are infected.

* The Public Health Service predicts a nearly 350% increase by 1991 to 3,000 cases; some experts predict as many as 10,000 to 20,000 pediatric AIDS cases by 1991.

ALREADY STRAINED SERVICES FOR PRENATAL CARE, FAMILY PLANNING AND DRUG TREATMENT, FACED WITH SOARING NUMBER OF WOMEN WITH OR AT RISK OF AIDS

* Nationally, over 3,000 AIDS cases have been reported in women, most of whom are of childbearing age.

* This number is expected to increase 600% to over 20,000 by the end of 1991.

* 30% - 50% of the babies born to HIV-infected women are also infected.

* In New York City, about 3% of women of reproductive age (approximately 50,000) are infected with HIV; most were exposed to the virus through intravenous drug use or sexual contact with an HIV-infected individual.

AIDS CLAIMING MAJORITY OF YOUNG VICTIMS IN COMMUNITIES LEAST ABLE TO FIGHT BACK

* Minority children, many of whom face urban poverty, poor health, lack of access to adequate care, and educational disadvantage, comprise the vast majority of pediatric AIDS cases.

* While black children are 15% of the total U.S. child population, 54% of all pediatric AIDS cases are black.

* Hispanic children are 10% of the child population, but 23% of the childhood AIDS population.

* White children, 75% of the population, represent 22% of all pediatric AIDS cases.

WHILE EXPANDED HOME AND NON-HOSPITAL BASED SERVICES PROMISE MORE HUMANE AND COST-EFFECTIVE CARE, HIV-INFECTED CHILDREN CHIEFLY TREATED IN EXPENSIVE IN-PATIENT HOSPITAL CARE

* Hospital care for infants born with AIDS can cost more than $200,000 per year per child.

* In contrast, Hale House Cradle, a planned group home in New York City for children with AIDS, is expected to cost $161 per day, or $58,765 per year for treatment and care, in contrast to $600 per day or $219,000 per year for acute care in a hospital.

* The St. Clair's Home, a transitional foster care facility in Elizabeth, New Jersey, has been providing home care since May 1987; at a yearly operating budget of $200,000, its five beds have been continously occupied.

PEDIATRIC AIDS THREATENS ALREADY OVERBURDENED FOSTER CARE SYSTEM

* Declining numbers of available foster homes combined with growing numbers of medically fragile and drug-exposed children have made appropriate placement of medically fragile children exceptionally difficult.

* Reduced availability of foster care has resulted in lengthy hospital stays for growing numbers of abandoned or orphaned children with or at risk of AIDS.

* New York City reported in July 1987 that at least 30 children with AIDS were boarding in hospitals. These "boarder babies" had been orphaned or abandoned and were awaiting foster care placement.

* Los Angeles County reported a 1000% increase between 1981 and 1986 in the number of infants and toddlers needing foster care for drug-related reasons, and increased referrals of sexually abused children -- both circumstances which place children at risk of AIDS infection.

ADOLESCENTS

NUMBER OF REPORTED AIDS CASES AMONG TEENS LOW, BUT ADOLESCENT BEHAVIORS PLACE THEM AT RISK

* While AIDS cases among 13-19 year olds represent only 0.4% of the total 47,298 reported AIDS cases, cases among this age group increased by 54% between January-November 1987 (from 127 to 195).

* By age 20, 70% of girls and 80% of boys have engaged in sexual intercourse at least once.

* Sexually active teens have the highest rate of sexually transmitted diseases among heterosexuals of all age groups.

* Increased heterosexual transmission of AIDS among teenagers and young adults has been confirmed by recent research.

ADOLESCENTS WITH HEMOPHILIA MOST HIV-INFECTED TEEN GROUP TO DATE

* 80% of AIDS cases among 11-17 year old males are hemophiliacs.

* 22%-75% of hemophiliacs have tested positive for AIDS antibodies; with the future safety of the blood clotting factor assured, the virus will no longer be transmitted in this way.

RUNAWAY AND HOMELESS YOUTH, AND MINORITY YOUTH IN URBAN CENTERS AT GREATEST RISK OF HIV INFECTION AND HARDEST TO REACH

* Out-of-school, runaway and homeless youth risk becoming infected because of higher rates of drug abuse and prostitution, and other behavior associated with HIV transmission.

* Minority youth also are at greater risk of AIDS infection due to their higher rate of sexually transmitted diseases, and their higher concentration in urban areas where the AIDS virus is prevalent.

ADOLESCENTS HOLD INAPPROPRIATE ATTITUDES AND BELIEFS ABOUT THEIR RISK OF AIDS INFECTION; PREVENTION DEMANDS APPROPRIATE AND CLEAR SEX EDUCATION BEGINNING AT EARLY AGES

* Only 15% of sexually active youth surveyed reported changing their sexual behavior to prevent contracting AIDS; only 20% of those who changed their behavior used effective preventive methods.

* Teens' denial of vulnerability and tendency to experiment and take risks makes AIDS education by itself insufficient.

* Only half of the largest U.S. school districts are providing AIDS education and prevention programs; programs to reach high-risk, out-of-school youth lag even further behind.

THE FEDERAL RESPONSE

FEDERAL EFFORTS TO COMBAT AIDS UNDERFUNDED, UNCOORDINATED, AND INSUFFICIENT

* A 1986 National Academy of Sciences report charged that the federal AIDS education effort was "woefully inadequate in terms of both the amount of educational material made available and its clear communication of intended messages."

* An August 1987 General Accounting Office review of AIDS prevention and the Administration's proposed 1988 budget reported a consensus of experts that federal efforts so far have been underfunded, uncoordinated, and insufficient.

LITTLE ATTENTION AND MONEY TARGETED ON AIDS PREVENTION AND TREATMENT FOR CHILDREN AND YOUTH

* Although children and youth are likely to benefit from most federal spending on AIDS, in FY 1987, only $6.5 million was made available by the Centers for Disease Control for school health prevention efforts. Only $16 million of the Administration's $422 million FY 1988 request for AIDS research at the National Institutes of Health would target children.

* $7.5 million of the National Institutes of Health's $252 million AIDS research budget for FY 1987 was dedicated to research exclusively on pediatric AIDS.

I. INFANTS AND YOUNG CHILDREN

A. AIDS AMONG INFANTS AND YOUNG CHILDREN INCREASING DRAMATICALLY

IN THE FIRST ELEVEN MONTHS OF 1987, THE NUMBER OF REPORTED AIDS CASES AMONG INFANTS AND YOUNG CHILDREN ROSE MORE THAN 60 PERCENT

The first cases of children with AIDS (Acquired Immune Deficiency Syndrome) were reported to the Centers for Disease Control (CDC) in December 1982. As of November 30, 1987, 691 cases of AIDS in U.S. children under 13 had been reported to the CDC, up by 271 cases or more than 60% since January 1, 1987. (62)

AIDS Cases Vastly Underreported

Childhood AIDS cases currently represent fewer than 2% of the 47,298 diagnosed cases reported thus far in the U.S. However, for both adults and children, experts agree that the number of reports received significantly underestimates the actual incidence of the disease. Dr. James Oleske, Director of the Division of Allergy, Immunology and Infectious Disease at the University of Medicine and Dentistry of New Jersey, reported to the Committee in May 1986, that the 350 cases of pediatric AIDS reported to the CDC at that time severely underreported the actual number, which he estimated to be closer to 2,000 cases. (45)

Dr. Moses Grossman, Professor of Pediatrics and Vice Chairman, Department of Pediatrics at the University of

California at San Francisco, concurred with Oleske in his testimony at the Committee's February 1987 hearing:

> I would like to echo those who said before me that the number [of reported pediatric AIDS cases] is under-represented in a very serious way. CDC for epidemiologic purposes has a very strict and very narrow definition of AIDS. For epidemiological purposes, it is fair enough, but if you think about children who need care, and how many of them there are, as of today, there are many, many more than that number. (23)

In addition to diagnosed cases of pediatric AIDS, many more children are thought to have milder forms of the illness, or are infected but do not show symptoms. Experts have estimated that for every child with full-blown AIDS, several others may be infected. (45; 33)

Until recently, according to the CDC, in order to be diagnosed as having AIDS, a child needed to have a reliably diagnosed infection with one of a specific list of organisms associated with immune deficient patients (e.g., an opportunistic infection) and have no other disease causing immune deficiency.1/

There are many children with AIDS-related illnesses whose cases have not been recorded by the CDC because they failed to meet the strict definition. For each case of AIDS in children, pediatricians estimate that there are 3 to 5 times as many

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1/ On August 14, 1987, the CDC published a revised case definition for AIDS "a) to track more effectively the severe disabling morbidity associated with infection with HIV (human immunodeficiency virus); b) to simplify reporting of AIDS cases; c) to increase the sensitivity and specificity of the definition through greater diagnostic application of laboratory evidence for HIV infection; d) to be consistent with current diagnostic practice, which in some cases includes presumptive, i.e., without confirmatory laboratory evidence, diagnosis of AIDS-indicative diseases." See Appendix II, containing revised guidelines.

children with AIDS-related illnesses. They also estimate that over a two to three year period, 20-25% of children with AIDS-related illnesses will acquire one of the life-threatening opportunistic infections that have denoted full-blown AIDS. (15)

Rapid Increase in Childhood AIDS Expected To Continue

There is every indication that childhood AIDS will increasingly become a major national public health problem. The U.S. Public Health Service estimates that by 1991, the number of children with pediatric AIDS will have increased to 3,000, and virtually all will die of the disease within 3 years. This is nearly a 350% increase from the current number, and according to Surgeon General Koop, "as frightening as this may sound, the number is undoubtedly underestimated." (33)

In New York City, Department of Health officials expect as many as 4,000 cases of pediatric AIDS by 1991. The Mayor's Task Force on AIDS in Washington, D.C., projects over 1,000 cases in that city by 1991. In New Jersey, the State Department of Health reported a 400% increase in the number of pediatric cases in the past year. (43)

The increases will come largely as a result of the growing number of women of childbearing age infected with the disease, since about 80% of AIDS cases in children result from perinatal transmission from the mother. Just over 3,300 cases of AIDS have been reported in women, 95% of whom are of childbearing age. This number is expected to increase to over 20,000 by the end of 1991. As more women become infected, more children born to these women will be infected. "HIV infection in children is likely to become a more common pediatric infection." (34)

Dr. Robert Benjamin, M.P.H., Chief of the Bureau of Communicable Diseases, County Department of Community Health Services, Alameda County, California, reported corroborating evidence to the Committee at the February hearing, based on the results of a survey conducted in that County:

> The January 1987 results of a blind study conducted in sexually transmitted disease (STD) clinics in Alameda County, California, showed a 0.5% seropositivity in women attending premartial testing sites. This means that approximately 1 in 200 women attending those clinics was infected....This information has potentially grave implications for the prospects of vertical transmission and the appearance of increasing numbers of children with AIDS and ARC. This study represents prevalence in the population almost one year ago. (10)

Dr. Lorraine Hale, Executive Director of Hale House in New York, which provides a group home environment for babies born to drug-addicted mothers, has also described the magnitude of the problem in New York State:

> Ten years ago, it was estimated that in New York State, there were 28,000 female drug users, 26,000 of child bearing age, [each] capable of giving birth to 3.5 babies over a 15 year period. Given today's statistics, we find there are 75,000 women in methadone maintenance programs. 63% or 47,250 have positive antibodies for the [AIDS] virus. They too are each capable of giving birth to 3.5 babies over a 15 year period, for a total of 165,375 babies, the vast majority of whom will also test positive for the antibodies. (25)

Extrapolating from test site data, experts now estimate that in New York City, there are some 50,000 women who are infected but presently asymptomatic, and most of them unaware. "They represent 3% of the City's women of reproductive age. The infection rate is thought to be 50% among women who use drugs and 20% among those whose mates are addicts." (11)

The drug abuse and AIDS connection is especially ominous for increased perinatal transmission of the virus. While drug use is estimated to have dropped in the country overall, drug abuse has continued or increased among the poor and least educated, particularly in urban epicenters where the AIDS virus is most prevalent. (69)

Geographic Spread of AIDS Virus Seen

Surgeon General Koop has also called attention to the increasing geographic spread of the disease. By 1991, according to the Public Health Service, 80% of all AIDS cases will occur in areas outside of New York City and San Francisco, the cities most heavily affected so far. (61)

In the early 1980's, childhood AIDS was localized in the New York, New Jersey, and Florida areas, reflecting the occurrence of AIDS cases in IV drug users (75% of whom are from New York or New Jersey) and among Haitian immigrants[2/] (79% of whom reside in Florida or New York). However, the proportion of AIDS cases among children reported from other states has increased from 24% in 1982 - 1984 to 34% in 1985 - 1986. "This trend in reporting is expected to continue over the next 5 years as the AIDS epidemic spreads to other areas in the United States." (34)

Survival Rates Are Low

Thus far, the survival rate for children with AIDS is low.

2/ A higher prevalence of AIDS has been reported among Haitians immigrants than among the general population in which prevalence remains low. Experts suggest the greater frequency of heterosexual transmission in the spread of HIV infection among the Haitian population than among the U.S. population as a whole, so far.

Of all children under 13 years of age diagnosed with AIDS, 60% are known to have died. (62) Of children diagnosed with AIDS before 1984, 75%-80% are known to have died. (45) As with reporting of active AIDS cases, deaths attributable to AIDS are also likely to be underreported.

The life span of infants with fully developed AIDS appears to be about one year after diagnosis. However, this period is highly variable; the final mortality rate for infected children is also unknown.

Oleske has reported that, as a result of the comprehensive program of care provided at Children's Hospital in Newark, New Jersey, the mortality rate of infants with AIDS has decreased. (46) Also, with the increasing sophistication of medical care, a few infected children have reached the age of 7-9 years and are reasonably healthy even though their immune systems are impaired. (51; 66) It is quite possible that some of these children will survive to sexually active young adulthood.

B. PEDIATRIC AIDS AND AIDS AMONG ADULTS DIFFER

The same virus, human immunodeficiency virus (HIV), causes AIDS among adults and among infants and young children by attacking and damaging their immune and central nervous systems. There are, however, many differences in the manifestations and course of the disease for the two groups.

Infection with the AIDS virus is more difficult to ascertain in infants especially because HIV-infected mothers may transmit HIV antibodies as well as the virus to their babies.

Infants who have a positive result on the antibody test[3/] at birth may later test negative, indicating transmission of the mother's antibodies but not HIV infection itself. Recent revision of the Centers for Disease Control Surveillance Case Definition for AIDS notes more stringent laboratory criteria for HIV infection among infants, "since the presence of HIV antibody in the child is, by itself, insufficient evidence for HIV infection because of the persistence of passively acquired maternal antibodies at less than 15 months of age." (See Appendix II.)

Infection with HIV manifests itself in a range of conditions and symptoms that differ in children and adults. In adults, symptoms of fully developed AIDS include the presence of opportunistic infections and/or rare cancers. Most deaths of adults with AIDS result from these conditions. The most common of these are Pneumocystis carinii pneumonia, a rare pneumonia, and Kaposi's sarcoma, a rare cancer that appears on the skin and can spread to internal organs. To date, close to 80% of AIDS patients have had one or both of these diseases. Other disorders associated with AIDS in adults are leukemia-like cancer, prolonged diarrhea leading to severe dehydration, weight loss, and infections of the central nervous system that can lead to neurological problems including dementia.

An HIV-related condition of a seemingly less severe nature, but which may also be very debilitating and life threatening,

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3/ There is now a simple test that can detect antibodies to HIV in the blood three weeks to three months after infection. This test does not directly show infection with HIV, but rather the presence of antibodies to the virus. The presence of antibodies is used as the indicator of HIV infection. In very unusual cases, an individual's antibody test may remain negative for a longer time; however, the virus can be passed on to others even before the antibody test is positive.

is termed AIDS-Related Complex (ARC), more commonly known as HIV-related illness. Symptoms of this condition may include enlarged lymph nodes, fatigue, weight loss, fever, and diarrhea. In addition, a large number of individuals who test positive for HIV antibodies may not have any obvious symptoms or illnesses at all. It is not yet clear how many of these asymptomatic individuals may become symptomatic, develop ARC, or develop full-blown AIDS.

In infants and children, the disease is generally characterized by failure to thrive and the appearance of unusually severe bacterial infections. Children with symptomatic HIV infection do not often develop as frequent or diverse opportunistic infections as adults, with the exception of Pneumocystis carinii pneumonia. More frequently, children suffer from recurrent bacterial infections, persistent or recurrent oral thrush (a common fungal infection of the mouth or throat), and chronic or recurrent diarrhea. Infected children may also demonstrate enlarged lymph nodes, chronic pneumonia, developmental delays, and neurologic abnormalities.

Infants and Young Children Most Frequently Infected Perinatally

Most HIV-infected young children became infected with the AIDS virus from their infected mothers during pregnancy. Many of the infected pregnant women were drug abusers themselves or had sexual partners who had HIV infection. A few young children have become infected with HIV by receiving transfusions of contaminated blood or blood products, through sexual abuse by an HIV-infected adult, or by contact with a contaminated needle.

The CDC has reported that among all AIDS patients under 13 years of age at the time of diagnosis, 76% had a parent infected with AIDS. Of the remaining 22%, 13% received a contaminated transfusion; 6% regularly received blood products because of a hemophilia/coagulation disorder; and 5% were of undetermined origin. (62)

> The epidemiological characteristics of these children closely parallel those of heterosexual adults with AIDS, particularly women. Over half (65%) of reported cases of AIDS in women, 69% of heterosexual men with AIDS, and 73% of the perinatally acquired AIDS cases in children were related to IV drug abuse or sexual contact with IV drug abusers. (50)

Although the transmission of AIDS during pregnancy is frequent, U.S. Surgeon General C. Everett Koop indicated that we cannot fully answer how infected mothers transmit the virus to their babies:

> In one study of mothers who had already delivered one infected baby, 50% transmitted the virus to their subsequent children. Transmission rates in other studies have been lower. Based on current knowledge, CDC estimates that about one-third to one-half of infected mothers will give birth to infected infants. (34)

He added:

> It is hypothesized that transmission could occur during pregnancy, through passage of the virus through the placenta; during labor and delivery, through exposure to infective maternal blood and vaginal secretions, or after birth, through breast feeding. There is evidence that transmission can occur through all of these modes. (34)

The fact that AIDS is transmitted through sexual contact also places child victims of sexual abuse at higher risk of contracting AIDS and ARC. Several doctors and social workers have reported treating a small number of children who, they believed, contracted AIDS as a result of sexual molestation by

an HIV-infected adult. (58) At the Select Committee's hearing in February on AIDS and young children, Dr. Moses Grossman told the Committee that there had been several reports of children who were infected as a result of sexual abuse, but that research on transmission due to sexual abuse was just getting underway.

Children whose environment includes the activities of IV-drug using adults are also potentially exposed to contaminated needles, another source of transmission for HIV virus which can lead to AIDS. For example, in New York, a 9-year-old girl who first showed signs of AIDS symptoms at age 7 is thought to have contracted AIDS by playing with contaminated needles used by her drug-abusing parents. (58)

C. MINORITY CHILDREN DISPROPORTIONATELY AFFECTED BY AIDS INFECTION

MINORITY CHILDREN, MANY OF WHOM FACE OBSTACLES OF POVERTY, POOR HEALTH AND LACK OF ACCESS TO ADEQUATE CARE, AS WELL AS EDUCATIONAL DISAVANTAGE, NOW HARDEST HIT BY AIDS VIRUS

Poor, urban, minority communities, which already face overwhelming problems and have the fewest resources, now are bearing the brunt of the AIDS epidemic. The AIDS virus first was reported and remains most prevalent in urban centers of the country where minority populations are large.

Individuals infected with AIDS virus are increasingly young, and black or Hispanic. According to the CDC, minorities make up less than one-fifth of the country's population, but account for more than one-third of the reported AIDS cases, with minority women and children facing the greatest risks.

Nearly 80% of all the children with AIDS are either black or Hispanic, and more than 70% of all women with AIDS are members of a minority group. (62)

As of November 30, 1987, the CDC reported that 375 or 54% of the reported AIDS patients under age 13 are black; 162 or 23% are Hispanic; 149 or 22% are white; and 5 or 1% are of other or unknown races. Black children represent only 15% of the total U.S. population of children, and Hispanic children represent only 10%. Most of these infants and children became infected during pregnancy; 85% of minority children with AIDS and 42% of white children were infected perinatally. (62)

William Barrick, R.N., M.S.N., Program Manager for the AIDS Project at Alta Bates Hospital in Berkeley, California, emphasized in his testimony before the Committee in February that:

> Of particular importance is the creation and expansion of services reaching Hispanic and Black mothers--the incidence of HIV infection in their children is already nine to fifteen times higher than among whites. (9)

Sylvia Villarreal, M.D., a Physician Specialist with the Department of Public Health for the City of San Francisco and a member of the Department's Minority AIDS Task Force, pointed out that the disparity in representation of minority children with AIDS reflects the greater incidence of poverty, low education and drug abuse among these children and their families. Villarreal told the Committee:

> Racial, ethnic and culturally specific and sensitive education must be financed and targeted for the communities of color. Previous models used for gay and white populations may not be appropriate or sensitive to the needs of diverse peoples. We must educate that it (AIDS) is a nonsexist and nonracist disease that attacks all. (65)

D. CARE FOR CHILDREN WITH AIDS SCARCE

Children with AIDS Face Multiple, Devastating Health Problems

Children with HIV infection are similar to severely premature infants or low birthweight babies. Their health easily deteriorates and highly specialized care is required. Oleske described many of these children as demonstrating "failure-to-thrive," noting:

> They have a special type of pneumonia. They have chronic diarrhea, swollen lymph glands, swollen liver and spleen. And most devastating is the recognition that maybe half or more have an encephalopathy. In other words, their brains are directly infected. And this, of course, introduces so many problems, as it relates to treatment and rehabilitation. Their immune system is depressed, just like the adults, and they are at risk of many opportunistic infections, many of them difficult to treat. (45)

Adequate Health Care and Related Services for Children is Lacking

Oleske characterized the treatment programs that are available for infants and children with AIDS as being "catch-as-catch-can." These programs have been developed without organized support in places where the concentration of patients is heaviest:

> Specific therapy programs for children are still not available. We try to provide rehabilitation services, because of the tremendous problems these children have, as I mentioned, related both to their encephalopathy, and also their deprived background....(The) programs need to be comprehensive, need to take into consideration both the medical issues and the psychological issues which are presently overwhelming....These children deserve good care, and they are not getting good care, because of the limited resources available to this tragic group of patients. (45)

Margaret Heagarty, M.D., Director of Pediatrics at Harlem Hospital Center in New York, noted that because most children

with AIDS come from poor families, they are often cared for in public hospitals. There, too, the problem of providing adequate care is acute:

> Public general hospitals, almost by definition, are embattled institutions that survive from hand to mouth.... The AIDS epidemic has placed enormous financial stress upon these public general hospitals that in the best of circumstances barely manage to survive economically. Moreover, it has not only affected the care of AIDS patients, but imperils the entire municipal health care delivery system of this and other cities in which substantial numbers of poor AIDS patients are to be found. (27)

Based on his experience with the AIDS Project in Berkeley, California, Barrick predicted that the demand for hospital and related services for infants and children will increase substantially:

> Infant services will be seeing unknown numbers of children with chronic and mortal disease. The danger of live-virus immunization of children with AIDS may cause such diseases as measles, rubella, and mumps to reappear among these children. Frequent office visits to pediatricians for close follow-up will become routine. In-patient treatment of infections will be far more frequent in this group. Acute care hospital admissions for diagnosis and treatment of neurological manifestations of AIDS will be more frequent. (9)

Barrick strongly urged in his testimony that prenatal health care providers work to identify HIV-positive mothers and advise them using many of the models developed for genetic counseling. In addition, he stated that perinatal care providers must take the appropriate precautions, as suggested by CDC, to protect the health care team during and after delivery of the infant; and postnatal services must be prepared for lengthy follow-up of the mother compromised by intravenous drug use and HIV infection.

Health care staff who care for AIDS patients will require

special training to gain a good understanding of the disease and provide appropriate care, as well as to protect themselves against HIV infection. The CDC have recommended that children with HIV infection be cared for by pediatricians knowledgeable in the management of AIDS. The CDC have also published extensive guidelines on the protection of workers in health care environments.

Growing Numbers of Children with AIDS Abandoned and Orphaned

INCREASINGLY, HOSPITALS ARE HAVING TO CARE FOR CHILDREN WITH AND AT RISK OF AIDS ORPHANED BY PARENTS UNWILLING OR UNABLE TO CARE FOR THEM

Some New York City hospitals and social service agencies have already been overwhelmed by the growing numbers of babies abandoned by their parents. These babies may already be ill with AIDS or test positive for the AIDS virus with no signs of illness. (44)

In February, Villarreal told the Committee that New York City was maintaining in hospitals HIV-positive children not clinically ill because of the inability to secure adequate placement.

By summer, Heagarty reported on the costliness of this extended but unnecessary hospitalization of "boarder babies." For the first 37 children with AIDS cared for in Harlem Hospital, 30% of the hospital days and 20% of the total cost were not medically necessary, but unavoidable because there were no other placements available for the children. (27)

While this situation has eased with the establishment of

specialized foster care placements and vigorous recruitment, problems remain. In July 1987, at least 30 children with AIDS who had been orphaned or abandoned and were waiting for foster families were boarding in New York hospitals. Further, in some cases when the City placed children with AIDS in foster care prior to diagnosis, foster parents have left the children in hospitals once the diagnosis was made, unwilling or unprepared to deal with the physical, emotional and financial burdens. Many of these abandoned children experience the fear and isolation common to the terminally or chronically ill.

> Many of them are also psychologically scarred because they were abandoned in hospitals. According to several experts in early childhood development, these children are often emotionally disturbed and developmentally delayed because of the absence of consistent one-on-one care. (58)

One such child was "Peter," who spent his first 5 years in a hospital:

> Peter (was) abandoned by parents who were drug abusers. He is making a ragged adjustment to foster care and seems more like an emotionally disturbed boy than a sick one, often separated from other children because of his unruly behavior. (58)

The director of a day-care center for AIDS children in Bronx, New York, reported that these children did not understand the difference between day and night or between friends and strangers. "They have no sense of cause and response, no sense of what a day is or when you do this or that. They also find transitions of any kind difficult, because any change symbolizes all the other comings and goings." (58)

Hospital settings, strained to care for increasing numbers of abandoned babies, have been referred to as "silent

nurseries." Everyone agrees that they are not designed, equipped or staffed to parent infants and young children.

Foster Care Placements Needed But Increasingly Hard to Find for Children with or at Risk of AIDS

Children with HIV infection who have been abandoned, or whose parents are themselves too sick to care for them, need safe and loving foster care. "The absence of a nuturing environment with adequate infant stimulation can compound AIDS-related or drug-related failure to thrive by developmental delay and growth failure secondary to maternal deprivation." (8)

Unfortunately, it has become increasingly difficult to find foster care placement for children with or at risk of AIDS.

The needs of these children must be addressed by an already beleaguered foster care system, once again experiencing growth in the numbers of children in care after an estimated decline from 500,000 in 1977 to 269,000 in 1983. (70) The estimated average monthly number of children in AFDC foster care in FY 1987, 109,000, was the highest of any year since 1980 (57). In a survey conducted by the Select Committee, of the 50 states and the District of Columbia, between 1981-1985, the number of children reported to have been abused or neglected rose 55%. (1)

The Committee's examination of homelessness early in 1987 documented also that increasing numbers of homeless families are forced to place their children in foster care because shelters are rarely set up to accommodate them. Tricia Fagan, Outreach Coordinator, Association for Children of New Jersey, told the Committee in February that because of the limited

number of family shelters, and because their parents could not find an affordable place to live, at least 1200 children in New Jersey were placed in foster care in 1985, representing 18% of that state's foster care caseload. (20)

Along with these crises, child welfare systems are faced with increasing numbers of children born to drug dependent parents who are too ill or unprepared to care for them properly. Now there is AIDS, and fear of the deadly disease has placed tremendous new demands on the system and created new barriers to foster care placement.

Jean McIntosh, M.S.W., Assistant Director, Los Angeles County Department of Children's Services in California, reported increases on the order of 1000% between 1981 and 1986 in the numbers of drug-related dependency petitions for infants and toddlers. She also reported increases in referrals of children who are the victims of sexual molestation. These are both circumstances which place infants and young children at risk of becoming infected with AIDS and potentially in need of out-of-home care:

> Nationally, recruitment of foster families for pre-school children is becoming more and more difficult due to social and financial considerations. Compounding this trend is the fact that those foster parents we do recruit are often afraid to care for such medically fragile children. Now, we are facing the alarming possibility that a significant proportion of these children are at risk of AIDS. It is not hard to imagine that potential foster parents may move away from caring for these vulnerable children to protect their own families. Given what we know about the social and physical isolation that is attendant to AIDS and even ARC, young children so afflicted may have significantly reduced hope for foster placement. Not only will the social costs be great; the fiscal ramifications for the foster care system are enormous. (40)

Joyce Thomas reported similar problems in Washington, D.C.:

> Infants at risk for AIDS because of their parent's illness or their own early symptomatology are difficult to place in the foster care system. We are confronted with such problems here in Children's Hospital. The difficulties in terminating the parental rights of AIDS children in foster care and in finding adoptive homes for them may create a new class of children for whom the permanency planning goals of the Adoption Assistance Act of 1980 remain elusive.4/ (59)

E. NEW EFFORTS TO SUPPORT AIDS SERVICES FOR CHILDREN PROMISING, BUT ADEQUATE HEALTH, SOCIAL SERVICES MODELS SCARCE

Localities with the greatest numbers of pediatric AIDS cases have responded by creating new specially designed services that offer promise of more adequate treatment and care of infected children. So far, existing programs are predominantly hospital-based, although a few are non-hospital based, and more are planned.

At Albert Einstein Medical Center in Bronx, New York, a comprehensive clinic, which includes a mother's support group, has served more than 200 children with AIDS -- the most in the country.

Also in New York, the City has financed a day-care center in the Bronx where 35% of the city's pediatric AIDS cases are found. Twenty AIDS children attend the center which provides them with regular companionship and stimulation and their parents with several hours of relief each day from the daunting task of caring for them. The New York Times has reported that:

> Social workers who seek homes for AIDS children said they made more placements in the Bronx than in other boroughs,

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4/ The Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272) includes protections and safeguards for children in foster care, and outlines procedures for more expeditious handling of foster care placements so that children can be reunified with their families when possible or provided a permanent placement.

in part because of the center, which also offers a weekly support group for mothers.

At Children's Hospital in Newark, New Jersey, a program for pediatric AIDS patients that includes early intervention, comprehensive rehabilitation, and support for families has helped to reduce the mortality rate among the children, and to improve their quality of life, by reducing recurrent episodes of serious infections. (46)

Two private foster care agencies in New York City now have special programs to find homes for AIDS children. A grant from the New York State AIDS Institute has enabled these agencies to offer parents additional assistance, including reimbursement for baby sitters and equipment such as washing machines. In New York, foster parents caring for an HIV-infected child receive more than twice the financial support than is ordinarily received for foster care reimbursements. (41)

The experience of one model foster care program operated by Leake and Watts Children's Home in New York suggests the following lessons for recruitment and retention of foster families to care for children with HIV infection, ARC or AIDS:

1. Recruiting foster parents is a difficult task that requires a multifaceted strategy using both formal and informal networks; media announcements generate a high volume of interest but the most appropriate candidates have been located through foster parent and community networking.

2. Successful recruitment depends upon finding foster parents who are well informed concerning the disease, are not afraid of contagion, and, it would appear, have some medical background/experience in caring for ill people.

3. Recruiting and keeping foster parents are made possible at our present level of knowledge about and treatment of AIDS by offering an exceptional boarding home reimbursement rate (even at this rate one month of foster care is less expensive than two days in the hospital!) with continued

> financial assistance during hospitalizations. Maintaining foster homes also requires intensive medical and psychological support services.
>
> 4. Because assisting foster parents and children places strong demands on staff members for support, information, and guidance, caseload size has to be small and staff members must work as a team, with flexibility. (24)

Also in New York, Hale House Cradle is scheduled to open in fall 1987. Based on the highly successful Hale House Center, which has provided a residence for the infants of drug-addicted women, the Cradle will provide a small residential facility for unrelated babies born addicted to drugs who also test positive for antibodies to the AIDS virus. A similar home, St. Clair's Home in Elizabeth, New Jersey, has been in operation since May 1987.

In recent testimony before the Subcommittee on Select Education of the House Education and Labor Committee, Virginia Anderson, M.D., who directs the Surgeon General's Study Group on Pediatric AIDS, called urgent attention to the fact that:

> Adequate social and health care delivery models for pediatric AIDS do not exist and must be developed along multidisciplinary lines. Case management utilizing a care team approach may prove best for both patient and care-giver. It is [the] consensus of pediatricians across the country that suitable humane alternatives to the costly hospitalization of abandoned infants must be developed. (8)

She added that

> In home day-care by trained foster parents who can access a support system of social workers, medical doctors and pediatric AIDS treatment and evaluation units, is urgently needed. (8)

Oleske has suggested the development of treatment and care models that would focus on AIDS as a family disease, to provide care to both the often sick mother and her baby together, perhaps building on strategies employed in WIC (Special

Supplemental Food Program for Women, Infants and Children)[5/] and other maternal and child health programs. He points out that the care system now typically treats the mother and child with AIDS separately and with little success. (47)

Donna Pressma, Executive Director of the Children's Home Society of New Jersey in Trenton, further supported the need to assist the family besieged by AIDS. Citing P.L. 96-272 and its major objective in child welfare services to maintain and preserve the natural family, she said

> This principle in both practice and philosophy must not be overlooked in attempting to serve children with AIDS or born addicted to drugs....Although the mothers themselves are infected, they could be capable of taking care of their infants with adequate medical and social supports....While we are fully cognizant of the fact that many...mothers of HIV infected or drug addicted children may not ultimately be capable of parenting their child, every effort must be made to first assess the needs of that mother and some attempt toward helping her with adequate parenting skills be made. When a determination is made that the natural parent is not capable of parenting the child, and is not expected to be able to parent, a termination agreement should be accomplished expeditiously in order to adequately plan for the permanent placement of the child. (48)

F. THE COST OF CARING FOR CHILDREN WITH AIDS IS ENORMOUS AND ESCALATING

HOSPITAL CARE FOR CHILDREN COSTLY; MAJORITY OF FAMILIES DEPEND ON PUBLIC ASSISTANCE

While costs have decreased as more efficient service options have been explored (including hospital and non-hospital

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5/ Special Supplemental Food Program for Women, Infants, and Children (WIC), authorized by the Child Nutrition Act of 1966, as amended, provides nutritious supplemental foods to pregnant and post-partum women, infants and children through age 4, determined to be at nutritional risk because of inadequate nutrition (as determined by a competent professional authority) and inadequate income.

based services), the costs of care for infants with AIDS have been extraordinary. A study conducted at Harlem Hospital in New York City of 37 infants and children with AIDS or HIV positive status revealed the costs for in-hospital care alone to be $3.4 million. The 37 patients had 6,035 in-hospital patient days with a cost range of $300-$2,400 per day. (43)

Hale reported in June that:

> The cost for monitoring one baby in Harlem Hospital for one day is $600 or $219,000 per year. Simple calculations reveal that the hospital care of Hale House Cradle will be $161 per day, per child or $58,765 per year.
>
> We expect Medicaid or foster care to pay for all of these children, in homes or in hospitals. In other words the American people will pay for the cost for the care of these infants. (25)

Given these enormous costs, payment for services for children is clearly a major problem. Dr. James Oleske told the Committee:

> We treat all their ongoing infections, which are many. We use special drugs for special situations. In particular, we use intravenous gamma globulin, a very expensive therapy, for these children to try to prevent infection. The cost of these sometimes are rejected and denied by the various health care providers....Our hospital in Newark, NJ -- Children's Hospital -- just about went [bankrupt], trying to take care of these children. They spent $186,000 [per year] in just IV gamma globulin alone, a medicine we give just once a month. (45)

The U.S. Department of Health and Human Services has estimated that given current trends in the number of child and adult AIDS cases and the cost of medical treatment, an estimate of the cost of personal hospital and out-patient medical care in 1991 is $8 billion. However, costs could reach as high as $18 billion. At the beginning of September, the administrator

of the Health Care Financing Administration told the Presidential Commission on the Human Immunodeficiency Virus Epidemic that by fiscal 1992, federal and state Medicaid spending on AIDS will jump sixfold from $400 million this year to $2.4 billion annually. (71) Projected costs specific to the treatment of children have not been computed.

More Effective and Cost-efficient Options Needed

There is good reason to believe that some of the current costs for hospital care for children can be avoided through better use of foster care, home health care and social services. For example, Hale indicated that in the new "group home setting" for the treatment of infants with AIDS called "Hale House Cradle" due to open as soon as final approval is obtained from New York State, the cost of providing treatment will be $161 per day, or $58,765 per year. (25) The St. Clair's Home, a five-bed transitional home in New Jersey, provides a home care environment for $150 per day. (47)

Barrick indicated that the "impact [of AIDS] on home health and social services will be extreme." In his testimony to the Committee, Barrick described the kinds of home health care and social services that would be required to allow children with AIDS to live at home when not in need of hospitalization. According to Barrick, case management will be needed to address issues such as parenting skills, AIDS infection control in the home, logistical support needed to secure appropriate medical follow-up, foster care, medical foster care, AIDS education of parents and foster-parents, community education, counseling, substance abuse rehabilitation, vocational training and the like.

Utilization of these home health care and social services would likely result in savings overall, compared to hospital care. In San Francisco, home health and case management for adults with AIDS have proven to be cost effective, cost containing, and more emotionally supportive and sensitive than hospital care. Barrick asserted that there is every reason to believe the same will be true of the pediatric population. Savings accrued through proactive use of home health and social services to adults, compared to admission to an acute care hospital without such services, range from 50 to 75%. (9) Recent estimates regarding the use of non-hospital-based services for adults with AIDS have suggested cost savings of about 40%. (39)

II. ADOLESCENTS

A. AIDS AND ADOLESCENTS: A TIME BOMB?

CURRENTLY, THE NUMBER OF AIDS CASES AMONG ADOLESCENTS IS LOW. HOWEVER, TEEN SEXUAL ACTIVITY, HIGH RATES OF SEXUALLY TRANSMITTED DISEASES, AND RECENT EVIDENCE OF INCREASING HETEROSEXUAL TRANSMISSION OF AIDS AMONG ADOLESCENTS SUGGEST RISKS FOR YOUTH ARE GROWING.

Fortunately, there have been many fewer reported cases of AIDS among adolescents than among adults or younger children. As of November 30, 1987, CDC had reported 195 cases of AIDS among 13-19 year olds, which represents 0.4% of the total 47,298 reported AIDS cases. Of the total AIDS cases among teens, 88 or 45% are white, 66 or 34% are black, 36 or 18% are Hispanic, and 5 or 3% are of other or unknown races. There were 9,859 cases among 20-29 year olds (21% of the reported AIDS cases). Because of the typically long latency between infection and the onset of symptoms of the disease, it is likely that many of these 20-29 year olds became infected as teenagers. Geographically, cases of AIDS among teenagers are clustered in New Jersey, New York, and Florida. (62; 35)

Surgeon General Koop told the Committee in June 1987:

> To date, only one percent of all AIDS cases has occurred among persons under age 20 (most of whom were infected by transfusion or perinatal transmission); about 21% of all cases have been diagnosed in the 20-29 age group. Since the time between infection with the AIDS virus and onset of symptoms may be several years, some proportion of those aged 20-29 who have been diagnosed with AIDS were most likely infected as teenagers. (35)

According to Karen Hein, M.D., of the Department of Pediatrics at Albert Einstein College of Medicine in New York, the low percent of AIDS cases among adolescents reflects the cumulative, not the current pattern of infection:

> Analysis of the most recent data from N.Y.C. underscores the fact that heterosexual transmission among inner city minority youth is a clear and present danger. It is difficult to get an accurate sense of HIV prevalence in the adolescent population since few have been tested as yet. Asymptomatic HIV infection in adolescents is likely to present as illness (AIDS or ARC) in young adults. It is critical to focus on adolescents because the risk of an HIV-infected teenager developing AIDS does not decrease over time, and the virus can be transmitted while the adolescent remains asymptomatic. (28)

Transmission and course of HIV infection in adolescents appears more like that among adult cases than HIV infection among infants and young children. Adolescents have chiefly become infected with HIV through receipt of contaminated blood and blood products, sexual activity with an infected partner, and drug abuse using contaminated needles.

The unique character of adolescence as a developmental period also makes attention to the vulnerability of youth to HIV infection especially warranted. At one of the Select Committee's earliest hearings in October 1983, Joan Lipsitz, then Director of the Center for Early Adolescence at the University of North Carolina, told the Select Committee:

> Adolescents' new sense of independence, of their personal destiny, their new ability to evaluate values, and their self-consciousness about their emerging sexual maturity make them more fragile than we like to acknowledge. (36)

Adolescence is a period of personal uncertainty yet, paradoxically, a period characterized by a sense of invulnerability.

These factors often lead to a good deal of experimentation, for many in terms of sexual behavior and for some in taking illicit drugs. Because AIDS transmission is directly linked with sexual contact and drug abuse, the potential for infection among adolescents is clear. The danger is especially great in areas of the country where the prevalence of HIV infection is highest.

Gay and lesbian youth present special concerns. Professionals working with this population report that these teens, in struggling with their sexuality, frequently may have anonymous homosexual encounters distant from home while maintaining and engaging in heterosexual relationships in their neighborhoods. (72)

Richard Gordon, executive director of the Youth Development Branch of the Sequoia YMCA located in Redwood City, California, who also testified before the Committee in June 1987, reported that juvenile delinquents, runaways, homeless youth, and victims of child abuse are even more at risk of exposure to the AIDS virus, because they are even more likely to be involved in sexual experimentation, prostitution and drug use. (22)

Sexual Activity Among Teens Puts Them At Risk of HIV Infection

Since the most frequent mode of transmission of the AIDS virus is through sexual contact, it is clear that teenagers may be very much at risk because of their behaviors. Studies have shown that over 11.6 million teens (70% of girls and 80% of boys) have engaged in sexual intercourse at least once by the time they reach age 20. It also had been estimated that more than one million teenagers become pregnant each year. (74) Despite the good news of a decline in the rate of teen

pregnancy from 1980 - 1983 (75), one million teen pregnancies and their associated risks are alarming.

Testifying before the Select Committee in June 1987, Surgeon General Koop said:

> American teenage females experience about one million unplanned pregnancies each year. These data indicate not only the extent to which teenagers are sexually active, but also the extent to which they might transmit the AIDS virus perinatally. (35)

Teen Rates of Sexually Transmitted Diseases Suggest AIDS Spread

Overall, the evidence suggests that sexually transmitted diseases (STDs) are the most pervasive, destructive and costly communicable disease problem confronting adolescents today in the U.S. Premature sexual activity in conjunction with ineffective methods of contraception place the adolescent at risk for STDs, including AIDS.

Sexually active teenagers have the highest rates of STDs among heterosexuals of all age groups. It has been estimated that 1 in 7 teens currently has a sexually transmitted disease; this means that approximately 2.5 million teenagers are affected by sexually transmitted diseases each year. (49) Chlamydia and gonorrhea are the most prevalent of all STDs.

Mary-Ann Shafer, M.D., Associate Director of Adolescent Medicine at the University of California, San Francisco, cited estimates that more than half of the 20 million STD cases reported yearly will occur in individuals under the age of 25; one-fourth will affect teenagers under the age of 18. Recent research indicates female adolescents have the highest rates of

STDs. For males and females, STD rates decline dramatically with increasing age. (52)

Shafer elaborated on the evidence:

> More adolescents are engaging in sexual intercourse and are initiating this activity at younger ages than 10 years ago. Fifty per cent of adolescents have initiated sexual intercourse by their sixteenth birthday and over 70% by their nineteenth birthday. Among sexually active adolescent girls aged 15-19 years, almost 2/3 of these girls use no or ineffective contraception, and less than 17% reported using a barrier contraceptive method at last intercourse (15% condoms, 3% diaphragms). It is these latter forms of contraceptives, the barrier methods, that can afford some protection against STDS, including AIDS. (52)

In his testimony before the Committee in June, Surgeon General Koop cited findings from the National Survey of Family Growth that about half of teenagers use some method of contraception at first intercourse; those who did use a method tended to use the condom. (35) The survey found that, among teens using contraception, the younger the teen the more likely the person is to use a condom than other methods. Because of this trend, it would seem that condom use is a teachable technique appropriate for sexually active adolescents.

Heterosexual AIDS Transmission Among Teens on Rise

The facts that a high proportion of teens are sexually active and that rates of STDs are highest among adolescents make young people especially vulnerable to heterosexual transmission of the AIDS virus.

A recent study of charts of more than 4,000 persons treated at an inner-city STD clinic found that 6.3% of the men and 3% of the women were HIV-infected. Of those with positive test

results, one-third of the men and nearly 50% of the women were infected heterosexually. (82)

Evidence of heterosexual transmission is suggested in the changing male to female ratio of AIDS infection. In the U.S., for all ages, the male to female ratio of AIDS victims is 12 to 1, reflecting the greater numbers of AIDS cases among male homosexuals. Recent research evidence suggests the concentration of AIDS infection among homosexual males may be leveling off or declining. At the same time, the concentration is increasing among other groups at risk, such as IV drug abusers, their partners and their offspring. Also, it appears that survival rates are lower among IV drug abusers with AIDS. At the end of October, health officials in New York City reported a study of deaths from 1982-1986, resulting in a higher number of deaths due to AIDS among drug addicts than among homosexual men. (3)

Results of the first six months of HIV testing of civilian applicants to the military revealed that of those testing positive for HIV antibodies, the male to female ratio was 2.69:1. This suggests a much higher level of heterosexual transmission of the AIDS virus than indicated in the total population of reported AIDS cases to date. Of the 460 applicants identified as HIV-antibody-positive, nearly 15% were teenagers (17 to 20 years of age).

> Seroprevalences increased directly with age from 18 years to 27 years, after which age-specific rates plateaued or tended to decline. These data suggest that teenagers and young adults have an appreciable risk of infection, and that the risk may be relatively constant and cumulative throughout this age group. (13)

The principal researcher, Dr. Donald S. Burke of the Walter

Reed Army Institute of Research in Washington, told Select Committee staff in an interview for this report that the subsequent year of testing has revealed an increasing prevalence rate among recruits, particularly among young black men where an increase of 25% has been observed between 1986 and 1987. (12)

Dr. Hein also provided evidence suggesting increasing heterosexual transmission of the AIDS virus among adolescents by noting that among New York City adolescent AIDS cases, the male to female ratio is 2.8:1.

In September 1987, a study of 118 New York youth ages 13 to 21 with AIDS, the majority of whom were black and Hispanic males, showed a much lower incidence of homosexuality or bisexuality (44%) compared to adults (66%), while a higher percentage were IV drug abusers (23% compared to 16% among all adults) or female partners of these two groups (11% compared to 2%). Eighteen percent of the New York City young male adolescent AIDS cases were transfusion recipients or hemophiliacs as compared to 80% of younger adolescent males in the rest of the nation. (29)

B. MINORITY TEENS ESPECIALLY AT RISK OF AIDS INFECTION

HIGHER PREVALENCE OF SEXUALLY TRANSMITTED DISEASES, COMBINED WITH MULTIPLE RISKS ASSOCIATED WITH POVERTY, PLACE MINORITY YOUTH AT GREATER RISK FOR AIDS INFECTION

To understand the possible impact of the AIDS epidemic on adolescents, Shafer said, it is necessary to understand the characteristics of the youth population, and the actual and projected scope of the problem of sexually transmitted diseases, including AIDS, among adolescents. (52)

The heightened risk of AIDS infection among minority youth comes at a time when the proportion of youth in the U.S. who are minority is rising rapidly. By the 1990's, a significant proportion of the country's adolescents will belong to a minority group. Currently, there are over 35 million youth 10-19 years of age in the U.S. More than 6.5 million are minority group members. Over the next decade, the adolescent population is expected to increase by about 10% with the greatest increases in population occurring in the West and Southwest. Ethnic minorities, especially Latino and Asian youth, will account for the largest increases in the adolescent population.

Shafer also noted that there is an increasing trend towards poverty among youth. By the 1990's, 25% of all families with adolescents will be headed by a single parent with 90% of these households headed by females. (In 1986, 34% of all female headed families lived below the poverty line; 50% of black female headed families and 51% of Hispanic female headed families were poor.) With the projected increase in single parent households, it is predicted that poverty will have a greater impact upon adolescents of the 1990's than on the youth of today.

The incidence of sexually transmitted diseases among minority youth is generally far higher than among their white counterparts.

Shafer told the Committee that the average age-adjusted gonorrhea rate in black males aged 15-19 years is approximately 15 times that for their white peers, and the rate for black females aged 15-19 is 10 times the white rate. Young black females had the highest prevalence rates of chlamydia (23%);

young Latino females had a prevalence rate of 14%; young white females, 10%. (52)

The greater incidence of STDs among minority youth, combined with demographic changes, will place more youth at risk for sexually transmitted disease infection (including AIDS) in the future given the established association between STDs (including AIDS) and poverty, minority, and younger age status.

C. HEMOPHILIA-ASSOCIATED AIDS INITIALLY SIGNIFICANT AMONG ADOLESCENTS

WHILE SEXUAL ACTIVITY IS CLEARLY THE MOST PERVASIVE RISK FACTOR FOR ADOLESCENT AIDS, A SIGNIFICANT NUMBER OF ADOLESCENT AIDS CASES THUS FAR ARE AMONG HEMOPHILIACS

In 1982, the first cases of AIDS in hemophiliacs were reported. Of the 184 cases of AIDS among teenagers reported through October 1987, 57 cases or 31% involved teens with hemophilia. Adolescent hemophiliacs represented 13% of the total of 440 hemophilia-associated AIDS cases. (76) Nationwide, among young adolescent males aged 11-17 years with AIDS, 80% are hemophiliacs. Of all the reported cases of AIDS among 20-29 year olds, 108 or 1% have hemophilia. Of all hemophilia associated AIDS cases, 24% are among 20-29 year olds. (76)

Louis M. Aledort, Professor and Vice Chairman of the Department of Medicine at the Mount Sinai School of Medicine in New York, told the Committee that, of all hemophiliacs, two-thirds (67%) are seropositive for HIV-virus. Depending on the type of clotting factor received, 22%-75% of hemophiliacs have tested positive for AIDS antibodies. With the future safety of the blood clotting factor assured, the virus will no longer be transmitted in this way, although some HIV-infected

individuals will progress to symptomatic AIDS. (5)

According to Aledort, the rate of newly reported hemophiliac related cases among all age groups has remained constant at about 30-37 cases per quarter since 1985. Aledort reported that the hemophiliac population probably has the highest prevalence of infection to date. (5) However, unlike others deemed at risk, hemophiliacs so far appear to have a low rate (2%) of progression from seropositivity to symptomatic AIDS. (77)

Aledort also estimated that 15% to 17% of the sexual partners of hemophiliacs with AIDS are now infected themselves. He told the Committee:

> A recent survey at our center revealed that although 98% of our responding hemophiliacs have acquired the majority of facts about the transmission of HIV, 51% do not practice safer sex. (5)

He added:

> Greater than 60% of all adolescents experience tongue kissing and are poor users of contraception -- condoms are very unpopular. These figures are as true for young hemophiliacs as for the general population. (5)

D. DRUG ABUSE, ADOLESCENTS, AND AIDS: PROBLEMS COMPOUNDED

WHILE NOT CURRENTLY PREVALENT AMONG ADOLESCENTS, INTRAVENOUS DRUG USE REMAINS A SERIOUS POTENTIAL RISK. IN 1985, 1.2% OF 16,000 HIGH SCHOOL SENIORS REPORTED HAVING EVER USED HEROIN.

Surgeon General Koop told the Committee that:

> About 1% of American high school seniors self-report having ever used heroin, 16.7% report having ever used cocaine, and 23.4% report having ever used stimulants; all of these drugs can be taken intravenously. Although teenagers generally do not inject drugs, those who do and share needles are at increased risk for infection with the AIDS virus. (35)

The spread of the AIDS virus by intravenous drug abusers poses a significant threat particularly to "street youth," who are more likely to be exposed to and engage in this high risk behavior, and to have sexual contact with individuals who might be HIV infected.

Adolescents who engage in other kinds of needle sharing behavior may also be at some risk. Gordon reported that his experience with teen runaways in California indicates that outside of urban areas the number of youths using IV drugs is relatively low. Gordon told the committee that in his affluent suburban area:

> Probably the group of youth most at risk for infection via shared needles are high school football players and other athletes who share needles for steroid injection. (22)

E. CARE FOR ADOLESCENTS: MULTIPLE CONSIDERATIONS

During the course of investigation for this report, the Select Committee discovered no evidence that the cost of providing medical care to adolescents with AIDS differed substantially from the cost of providing treatment to adults. Barrick estimated that the cost of care for adults ranged nationally from $60,000 to over $140,00 per case, depending primarily on the number of hospital days consumed per case.

However, Hein told the Committee that the cost of identifying and caring for adolescents with AIDS calls for a different type of analysis that goes beyond the direct costs of testing and patient care.

> Out-patient and in-patient insurance coverage for adolescents, particularly those who are not in school and who

> are from 'working poor' families is often inadequate or non-existent. The greatest demand will probably be for ambulatory care. The usual barriers keeping adolescents from obtaining care (payment, consent and confidentiality) are particularly relevant in relation to HIV infection. (28)

Further documentation of the barriers faced by adolescents came from Deborah Chollet, Ph.D., Senior Research Associate at the Employee Benefit Research Institute, who told the Committee that in 1985, 20% of all children under 18 and 33% of all children living in families whose income was below the poverty line were uninsured. The specific percentage of adolescents without health insurance was not analyzed. (78)

According to the National Center for Health Statistics, in 1980, 3.7 million or 15% of 12-17 year olds had no private or public health insurance coverage, or had only part-year coverage. (79)

The indirect costs to society for related services and lost productivity must also be considered. Recent estimates indicate that in 1991, the total indirect morbidity and mortality expenses associated with AIDS, including loss of productivity and premature mortality, will be more than $55 billion, as much as $45 billion more than direct medical costs. (55)

John Williams, Executive Director of Children's Hospital at Stanford in Palo Alto, California, addressed the issue of the cost of AIDS treatment for hemophiliac patients in addition to other medical expenses at the Committee's February 1987 hearing in Berkeley.

> Hemophilia is a very expensive health problem. The annual cost for the clotting factor concentrates varies from as

> little as $1,000 for a mild case to $75,000 for severe problems....AIDS is an additional financial catastrophe for children who already have the catastrophic health condition of hemophilia. For example, the cost for one of our children was $244,000 for the last year before he died. (67)

Aledort also testified that, for the hemophilia population, the need is great and the associated costs high for psychosocial and educational services, and staff training and support.

> Appropriate personnel are hard to find, but it is much more difficult to pay for them once you've found them. Reimbursement in the medical setting for these services is almost nonexistent in either the public or private insurance sector and we have seen hardly any educational funds trickle down to our centers. (5)

Hein recently reported the establishment of the Adolescent AIDS Program at Albert Einstein College of Medicine, Montefiore Medical Center, in New York. It is the first multidisciplinary program that is exclusively addressing the complex medical, psychosocial, ethical and legal issues of HIV infection and adolescents.

F. PREVENTION STRATEGIES TO STEM SPREAD OF AIDS AMONG ADOLESCENTS LIMITED

Adolescents' Sense of Invulnerability and Lack of Knowledge about AIDS Make Preventive Education Difficult

Although teenagers are clearly at risk of becoming infected with the AIDS virus, most teenagers do not believe they are. In his testimony before the Committee, Surgeon General Koop cited a recent survey of adolescents which appeared in the May 1987, issue of Pediatrics:

> A random sample of 860 Massachusetts youth aged 16-19 revealed that while 70% reported they were sexually active only 15% of them reported changing their sexual behavior because of concern about contracting AIDS; and only 20% of

those who changed their behavior used effective methods. (35)

In her testimony, Hein also described various characteristics of adolescent psychological development that are important in considering educational interventions to prevent AIDS infection.

> Teenagers tend to feel invulnerable, making a future risk of AIDS appear remote. This is compounded by the tendency toward "concrete" rather than "abstract" thinking still prevalent among adolescents. Decisions are thus based on very tangible factors rather than on long term probabilities. Peer pressure is an immediate and important factor that can override abstract and distant risks. The tendency toward denial, shared by all age groups, may be exaggerated in adolescence. (28)

A recent study by DiClemente, et al, described to the Committee by Shafer, also points to the lack of good information among teenagers about AIDS. To assess the needs of San Francisco high school students in order to develop an appropriate and relevant AIDS curriculum in the schools, the investigators administered an AIDS Information Survey to 628 students aged 14-18 years. The survey was a self-report questionnaire consisting of 30 items which assessed a student's knowledge, attitudes and beliefs regarding AIDS. The students surveyed included 141 Latinos, 226 blacks, and 261 whites. Fifty-two percent of the students were male. (17)

The survey results supported the hypothesis that adolescents lack sufficient knowledge about the cause, transmission, and prevention of AIDS, particularly about the preventive measures to be taken during sexual intercourse, including the use of condoms. For example, while "92% of the students correctly indicated that 'sexual intercourse was one mode of

contracting AIDS,' only 60% were aware that 'use of a condom during sexual intercourse may lower the risk of getting the disease.'" In addition, only about two-thirds of the surveyed students knew that AIDS was not spread through casual contact.

Shafer also noted that the research showed:

> Significant ethnic differences were identified in knowledge of AIDS, perceived risk of acquiring AIDS, and in the presence of misconceptions about AIDS transmission through casual contact. Whites were found to be the most knowledgeable, and latinos the least knowledgeable, with black youth intermediate in their knowledge of the cause, transmission, and prevention of AIDS. Minority youth were approximately twice as likely as white youth to have misconceptions regarding acquisition of the virus through casual contact. Youth, especially minority youth, who had less knowledge and more misconceptions about casual transmission of the virus, were likely to perceive themselves as more susceptible to the virus than their more knowledgeable peers. (52)

Shafer told the Committee that such findings have important implications in the development of an intervention for adolescents regarding AIDS as well as other STDs. Since prevention is the key "tool" regarding STDs in adolescents, it is imperative to design intervention programs which will effect change in knowledge, attitudes, and beliefs and will prevent or modify behaviors which place the adolescent at risk for STDs, including AIDS.

Shafer emphasized that intervention strategies become important when considering adolescents who are in the process of establishing "adult" health and behavior patterns. She pointed out that this is a period when youth may be particularly amenable to change through intervention. Experts note that this process of education to change attitudes and behaviors will be long term.

AIDS Education: What Students Need to Know

The Surgeon General has emphasized that it is most important that teenagers receive education that specifically would enable them to understand and avoid behaviors associated with transmission of the AIDS virus.

> A single pamphlet, a single filmstrip, a single lecture about AIDS will not be sufficient. Similarly, education about the biology of the virus, the symptoms of the disease, or the social and economic consequences of the epidemic will do little to influence its spread. Programs need to be designed specifically to help teenagers adopt the kind of behavior which will keep them from contracting this disease. (35)

Pointing out that abstinence from sexual intercourse until young people are ready to establish mutually faithful, monogamous relationships is the only certain way to prevent AIDS infection through sexual contact, the Surgeon General also has stated repeatedly that sexually active persons, including youth, need to learn about the proper use of condoms to protect themselves and their partners against HIV infection. (35; 80)

> Because about 70% of adolescents are sexually active, it's very difficult to get them to change that activity, and that is when, if they haven't listened to the message of abstinence or monogamous relationships on a long-term basis, you have to introduce such things as condoms, knowing that it offends the sensitivities of some people but, on the other hand, as a health officer, and even knowing that condoms are not 100% safe, there is little that I can do except to offer that to youngsters who are sexually active. (35)

The Surgeon General added that "when we talk about condoms, the education that goes with that has to be extraordinarily explicit."

The Surgeon General also emphasized the need for starting

appropriate education early:

> If you wait until a child is an adolescent and is fighting all these new urges and feelings for himself, it's very hard for him to approach sexuality in an abstract way. That's why I think most people who are concerned about the sexual activity of our teenagers believe that we have to build these foundations before they themselves go through puberty.... (35)

At the Committee's February hearing, Quackenbush further pointed out that:

> ...if we do not begin AIDS education until the middle of high school, a small but significant number of children will already be engaging in risk behavior before they receive the prevention information. Two, young children need help understanding the concept of "not casually transmitted." The diseases that young childen are familiar with are, for the most part, very easily transmitted and they have a hard time understanding sometimes that they are not at risk to contract AIDS in their normal affairs with playmates, students, and their families. Information as essential as AIDS prevention needs to be repeated over a period of time for it to be fully comprehended. We expand our opportunity to do this and to provide this information and education effectively by starting early. (49)

AIDS Education: What's Happening in Schools

SURVEY OF THE NATION'S LARGEST LOCAL SCHOOL DISTRICTS FINDS ONLY HALF PROVIDE SOME FORM OF AIDS EDUCATION

In his testimony before the Committee in June 1987, Jonathan Howe, President of the National School Boards Association, underscored the importance of developing AIDS education policies and programs:

> AIDS education cannot be an optional activity for schools -- it is something we must do, because school-age students are a primary AIDS risk group, and AIDS is a life-and-death issue. Many of the new cases will be young people. Even when a preventive vaccine is developed, it will not protect those already exposed. This leaves us with only one way to

prevent the further spread of AIDS -- and that is through education. (31)

Howe pointed out that one of the problems facing educators is the lack of good information. He explained that what is needed is a depth of understanding that can be incorporated into comprehensive curricula that address many levels of health and sex education throughout the elementary and secondary schools.

Howe added, however, that schools are lacking sufficient resources to do the job that they need to do.

We need help. We need financial resources, and you're absolutely correct, we must have some financial resources for research and the development of a model curriculum. (31)

The National Association of State Boards of Education reports that only nine states have mandated an AIDS education policy, with action pending in six additional states. (83)[6/]

According to Surgeon General Koop, information gathered during the winter of 1986 showed that 40 of the Nation's 73 largest school districts were providing education about AIDS, and 24 of the remaining 33 districts were planning such education. Of the districts that provided AIDS education, 90% provided it during 10th grade, 63% provided it during 7th grade and 60% provided it during 9th grade.

Johnnie Hamilton, Science Coordinator for Fairfax County

6/ On December 2, 1987, that National Association of State Boards of Education reported an update of the preliminary survey. According to the survey, 18 states now mandate some AIDS education. (84)

Public Schools in Virginia, told the Committee that Fairfax, the 11th largest school district in the nation, has developed a very comprehensive health education curriculum from the early grades upward that stresses responsibility and morality. AIDS education has been blended into this course of instruction.

> Our students are encouraged to just say no to many types of exploitation and negative peer pressure, both sex and drug related; however, we know that some students are sexually active and are drug users, and our AIDS instruction also addresses their need for life-saving information. (26)

Hamilton also reported to the Committee that in response to community inquiries, Fairfax is currently reviewing AIDS education materials suitable for 5th and 6th grade students.

Experts have urged that to assure that curricular materials are factually correct and age-appropriate, educational material be developed by education professionals and health experts working together. Howe cited an example of health and education professionals working together on curriculum development in Eugene, Oregon, where the curriculum was written by a classroom teacher, a health teacher, and a registered nurse; technical review was provided by two state health officials with AIDS expertise.

In October 1987, the U.S. Department of Education issued a handbook entitled "AIDS and the Education of our Children." The handbook is described by William Bennett, Secretary of Education, as "a scientifically accurate and morally serious contribution to AIDS education." (60) The Department intends to distribute copies of the handbook to principals, school boards, parents' groups and other educators.

AIDS Education: A Parent/Student/Community Partnership

AIDS EDUCATION FOR CHILDREN NOT ONLY A JOB FOR SCHOOLS -- PARENTS, TEENS AND COMMUNITY PROGRAMS ESSENTIAL

Surgeon General Koop along with the educators who testified before the Committee emphasized involvement of parents as an essential part of any education effort on AIDS for school-aged children.

Wayne Lutton, Ph.D., Research Director for The Summit in Manitou Springs, Colorado, told the Committee that an efficient and inexpensive means of reaching school children with information about AIDS would be for teachers to give responsible information directly to the parents.

In addition, Lutton stated that:

> A copy of all public school materials dealing with AIDS and sexuality should be placed in local public libraries so citizens can have easy access to them. This should be done voluntarily by the schools, ordered by the school boards or mandated by state law. (37)

The first AIDS hotline run by high school students for the community was established in Montgomery County, Maryland, through the Health Education Resource Organization (HERO). Operating 7 days a week, 8 AM to midnight, the hotline received over 4,000 calls a month from concerned adolescents and their parents who had questions and fears about the AIDS epidemic.

Becky Adler, a senior high school student and Teen AIDS Hot-liner told the Committee in June that:

> The teen years are times of experimentation and new options. Americans are becoming sexually active younger and younger, and those who do abuse drugs usually start as teenagers. So, if there is such a thing as a "high-risk" group -- it is teen America. And we at the Teen AIDS Hotline are working to save our generation. (2)

The Teen AIDS Hotline was conceived as one of several "family-oriented" programs to educate the community about AIDS. Other program examples include a Teen and Family Conference on AIDS held every weekend at neighborhood churches or synagogues; PTSA AIDS Night, an evening of education and dialogue about AIDS in the community for the entire family; and the Teen Internship Project, where teens are trained to educate their peers about AIDS and AIDS prevention.

The Teen AIDS Hotline was discontinued at the end of June 1987, because of lack of funding. The Teen AIDS Hotline was reconstituted under the auspices of the Maryland AIDS Foundation in August 1987.

Out-Of-School, Runaway and Homeless Youth Require Special Outreach

NATIONALLY, ABOUT 25% OF YOUTH DO NOT FINISH HIGH SCHOOL, CREATING A NEED FOR AIDS EDUCATION FOR ADOLESCENTS OUTSIDE SCHOOL SETTINGS.

Gordon reported to the Committee that:

> Runaway and homeless youth may be involved in juvenile prostitution and drug sales. Youth who have been sexually molested become "sexualized" and are more likely to be involved in sexual activity. When these young people are sheltered or incarcerated in runaway facilities, juvenile detention centers, or protective group homes they are often in same sex facilities where there may be increased homosexual activity or homosexual rape. (22)

Compounding the high risks that runaway and homeless youth face, these adolescents are exceptionally difficult to reach for purposes of prevention education or care. Child welfare professionals point to the tremendous need for outreach services to these adolescents with strong guarantees of confidentiality. (53)

Community leaders on the Board of Directors of the Sequoia YMCA in Redwood City instituted the Youth Development Branch 10 years ago to serve out-of-school youth. This program includes a juvenile court diversion program, two shelters for runaway youth, a drop-in center for homeless youth, and a long-term residential treatment center for youth who are victims of child abuse or have other emotional problems.

In response to concerns about out-of-school, runaway and homeless youth, the Youth Development Branch launched the AIDS Education Project for Sheltered and Incarcerated Youth. The goal of the AIDS Education Project was to develop a prevention curriculum specifically designed for youth in institutional settings and to provide training for the staff of those institutions in San Mateo County. An initial curriculum was developed based on input from an advisory panel of medical, health education, and public education experts.

Gordon told the Committee:

> Our curriculum was designed to meet the specific needs of the institutional setting. In the institutional setting, youth are transient and there may be only one opportunity to provide information and no opportunity to provide for follow-up discussion. One other important aspect of our work has been the education of the institutional staff. To date we have certified 46 staff in the County juvenile facilities to provide this AIDS prevention education.

> Educated staff can guarantee that the institution affirms risk reduction. (22)

The New Jersey Department of Health has also developed an outreach to those hard-to-reach populations who may be at risk, including out-of-school adolescents. One outreach program is training ex-addicts to go back into the streets and share information about AIDS and the drug-use connection. Additionally, mobile vans have been put to use to frequent low-income neighborhoods in cities with a high proportion of AIDS cases, such as Jersey City and Newark, New Jersey. These neighborhoods harbor many of those adolescents who have run away and are homeless. Physicians and social workers who staff the vans provide information about drug abuse and its side effects, including its connection to AIDS and how to prevent exposure to the AIDS virus. (56)

III. LEGAL AND ETHICAL CONSIDERATIONS[7/]

A. AIDS AMONG YOUNG CHILDREN AND ADOLESCENTS RAISES COMPLES ISSUES

As a result of the growing AIDS epidemic, society is struggling with complex legal and ethical issues, such as testing, the right of privacy, protections against discrimination, and duty to warn, in dealing with adults with or at risk of AIDS. The issues appear, in many cases, even more difficult in addressing concerns about children and youth, especially adolescents. In addition, issues uniquely concerning children are raised. Three main groups of issues will be raised here: (1) issues concerning medical treatment and testing which arise because of the age of the child; (2) privacy issues; and (3) issues concerning discrimination, especially relating to access to education.

Medical Treatment and Testing

With regard to infants and young children, decisions regarding care and treatment because of HIV infection are typically handled in the same way as they are dealt with for other conditions. Since infants and young children are unable to make meaningful judgments concerning medical intervention, parents or legal guardians generally hold the authority for decisions regarding straightforward treatment. The matter becomes more complex when considering a child's participation

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7/ This section was developed with assistance of the Congressional Research Service's American Law Division, in conformance with a request of the Select Committee. The section does not necessarily represent the opinion of CRS.

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in medical research. At the Surgeon General's conference on pediatric AIDS last spring, it was noted:

> Although the potential benefits of participation in research protocols (extended life or an improved quality of life) may often be substantial, many of these research protocols also may present substantial risks to the child. What are the decision-making processes that will maximize the potential benefits of medical science to the non-consenting child while protecting his or her fundamental rights? (21)

In addition, similar to the discussion concerning adults, questions have arisen regarding medical confidentiality for infants and children with HIV infection and the duty to warn those who, without adequate information and protection, may risk becoming infected because of extensive, non-casual contact, such as in medical or foster care.

Adolescents with and at risk of AIDS raise these and additional questions. Although minors, adolescents may consent to diagnosis and treatment of other sexually transmitted diseases. However, AIDS is unlike other STDs because so far it has no satisfactory treatment and it leads to death.

In her testimony before the Committee, Hein posed several ethical and legal questions pertinent to screening adolescents.

> Do adolescents have the right as a minor to participate in screening if it were available? Do they have the right to refuse, such as the mandatory screening for the military, Job Corps or Peace Corps? If they are screened, do they have the right not to be told the results? Should they have access to anonymous testing?...Should parents be involved, again, in the decision to be tested? What about if, at result time, if the results are positive, should parents be notified? If so, this would be quite different from other STDs....How can we inform immature minors about the issues involved in testing and in being positive? What about their partners who, themselves, are minors? What about case contacting? (28)

Recently, Abigail English, staff attorney, National Center for Youth Law in San Francisco, California, called attention to other legal issues relevant to HIV infection in adolescents:

> What is the scope of the confidentiality protection for an institutionalized adolescent known to be infected with the virus? Who, if anyone, is liable if disclosure of an adolescent's antibody status results in discrimination or other harm to the adolescent? (19)

She further pointed out how efforts that appear to be in the best interest of one age group may not be appropriate for another group. Citing a then-pending legislative proposal in California which would allow the testing of wards of the juvenile court, English commented that

> this statutory provision may be intended to allow the juvenile court to order the HIV test for infants born to drug-addicted mothers, but the authority it confers on the juvenile court <u>may</u> be used by <u>another</u> judge in <u>another</u> context to compel adolescent runaways to submit to involuntary testing. (19)

Mary-Ann Shafer in her testimony before the Committee in June also raised specific reservations about testing adolescents:

> Regarding testing, especially with adolescents, I have a big concern....If you require and mandate testing, that may backfire in that the groups that you want to reach with the counseling...to essentially change behaviors...won't enter the system and get that really in-depth counseling that's required. (52)

Vernon Mark, M.D., Associate Professor of Surgery, Harvard Medical School, Boston, presented another point of view in his testimony before the Committee. Mark suggested that repeated HIV testing is needed for epidemiologic purposes to see how

far and into which groups of the population the epidemic is spreading. (38)

Benjamin and Hein pointed out to the Committee that seroprevalence studies for purposes of epidemiology can be done through unlinked anonymous testing. Hein has added that this strategy can be coupled with voluntary confidential testing with age-appropriate pre- and post-test counseling. She recently commented that these approaches are "completely contrary to the current policies of mandatory testing for Job Corps, Peace Corps, the military and of dependent minors of certain federal agency employees." (29)

Privacy

One of the main issues raised by public health measures regarding AIDS is the question of the right of privacy for the person tested. This issue involves questions regarding federal and state constitutional rights, statutory provisions and common law actions. The resolution of the issues may turn on numerous factors including whether testing is voluntary or mandatory, whether there is consent to disclose results, the purpose of disclosure, and the application of specific statutory provisions. Legally, the issue has been seen in terms of balancing the individual's right to privacy against the need for society to know.

The public health community has generally agreed on the need for some type of confidentiality. Mark, in his testimony, also stated, "If we are going to resort to testing, we have to require confidentality." (38) Surgeon General Koop has stated

publicly that it is absolutely essential to ensure confidentiality.

With regard to school-aged children, both CDC and the American Academy of Pediatrics (AAP) recommend that school and health officials respect the right to privacy of any student infected with the AIDS virus. (See Appendix II)

In their Recommendations and Guidelines, (Aug. 30, 1985), CDC states:

> Parents of infected children should be aware of the potential for social isolation should the condition of the child become known to others in the care or educational setting. School, day-care and social service personnel and others involved in educating and caring for these children should be sensitive to the need for confidentiality and the right to privacy in these cases. (See Appendix II)

And, according to the AAP:

> The number of personnel aware of the child's condition should be kept to the minimum needed to assure proper care of the child and to detect situations in which the potential for transmission may increase. (6)

The rapidly evolving nature of the AIDS epidemic among young children and adolescents suggests the importance of advice given by English, urging "very careful development and evaluation of any recommendations specific to children and youth." (19)

Nondiscrimination and Access to Schools

Prevention of discrimination against adults with active AIDS or positive HIV-antibody test results has been the focus of considerable debate. English has pointed out several special problems with respect to discrimination against minors:

> First, most antidiscrimination laws do not speak to the specific settings in which minors may suffer the most threat: in the juvenile justice system; in schools; and in the foster care system. Second, while children and adolescents are entitled to protection of their constitutional rights, including privacy, the courts have applied different standards, in some cases less stringent standards, in evaluating burdens on the constitutional rights of minors, because of their vulnerability and immaturity, and because of the presumption that their parents, or the state acting in loco parentis, will act in their best interest. Third, adolescents [in particular] have more limited ability to advocate for themselves than adults do, and far more limited access to attorneys and other advocates. (19)

There are two main federal statutes which could affect the rights of children with a positive antibody test for the AIDS virus: section 504 of the Rehabilitation Act of 1973[8/], and P.L. 94-142, the Education for All Handicapped Children Act[9/]. Section 504 could affect the rights of children in areas such as employment or transportation, but the primary import of both these statutes for children may be in their possible requirements for access to education. Before analyzing this particular legal issue, it is helpful to note that CDC has published guidelines concerning access to education.

CDC, along with many state education and health departments, has recommended that most children infected with the AIDS virus be allowed to attend school. In its recommendations

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8/ 29 U.S.C. section 794. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against otherwise qualified handicapped individuals solely by reason of their handicap in any program or activity that receives federal financial assistance or in an executive agency or the United Postal Service.

9/ 20 U.S.C. sections 1400 et seq. P.L. 94-142, The Education for All Handicapped Children Act amended The Education of the Handicapped Act, which authorizes a number of programs to support and improve the education of handicapped children. The largest is the State grant program, designed to assure that every handicapped child aged 3-21 years, residing in a state that participates in this program, receives a free appropriate public education in the least restrictive environment.

on education and foster care of HIV-infected children, CDC explains that:

> None of the identified cases of HIV infection in the U.S. are known to have been transmitted in the school, daycare or foster care setting or through casual person-to-person contact. (See Appendix II)

Specifically, children with HIV infection do not transmit the infection by sharing eating or drinking utensils, coughs or sneezes, or casual kissing on the cheeks or mouth. In addition, although HIV-infected children may themselves face greater risk of infection in a group setting because of their immune system deficiencies, CDC has indicated that, "for most infected school-aged children, the benefits of an unrestricted setting would outweigh the risks of their acquiring potential harmful infections in the setting and the apparent nonexistent risk of transmission. These children should be allowed to attend school and after-school day-care and to be placed in a foster home in an unrestricted setting." (See Appendix II)

A survey conducted by the National Association of State Boards of Education in June 1987, indicated that, at that time, a majority of states (39 states) had policies or a position statement on admitting students with AIDS to schools. (42)

Guidelines issued by CDC note that decisions regarding the kind of educational and care setting for the child infected with the AIDS virus "should be based on the behavior, neurologic development, and physical condition of the child and the expected type of interaction with others in that setting," and that each case should be evaluated individually by a team that includes the child's physician, public health officials, the

child's parent or guardian and personnel from the care facility or school. (See Appendix II)

For preschool-age children and for some neurologically handicapped children, such as those who lack control of body secretions, CDC recommends a more restricted environment such as a setting that minimizes exposure of other children to blood or bodily fluids.

Both section 504 and P.L. 94-142 could be used as a possible statutory basis for a right to education for children infected with the AIDS virus. Section 504 prohibits discrimination against an otherwise qualified handicapped person solely by reason of handicap in any program or activitiy that receives federal financial assistance.

The issue of whether this section would cover persons with AIDS, ARC, or a positive blood test for antibodies to the AIDS virus is one of the most discussed legal issues involving AIDS. The Supreme Court in School Board of Nassau County v. Arline,[10/] held that a person with the contagious disease of tuberculosis may be a handicapped individual under section 504 and that the fact that a person with a record of an impairment is also contagious does not limit the coverage of the section. The Court further found that the issue of whether such contagious individuals are protected by section 504 is determined by whether such an individual is "otherwise qualified." In determining whether an individual is otherwise qualified, the Court found that an individualized inquiry must be made concerning the nature of the risk, the duration of the risk, the severity

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10 94 L.Ed.2d 307 (1987)

of the risk and the probability that the disease will be transmitted. A court must then evaluate whether reasonable accommodation is possible.

It has been suggested that the Supreme Court's reasoning in Arline would be applicable to children who are antibody positive for the AIDS virus and who manifest physical symptoms of the disease. The issues regarding children who are only antibody positive are less certain but an argument could be made that such children would also be handicapped persons for the purpose of the Act. In a recent California case, Thomas v. Atascadero Unified School District,[11/] an injunction was issued based on section 504 precluding the exclusion of an HIV-infected child from attending his kindergarten class. The court found that the child was otherwise qualified in the absence of evidence that the child posed a significant risk of harm to his teachers or classmates.

In November 1987, the U.S. Court of Appeals for the Ninth Circuit overturned a lower court's denial of injunctive relief and found that the plaintiff had a strong likelihood of prevailing in his allegation that he was discriminated against under section 504.[12/] The court ordered the reinstatement of a California teacher with AIDS who had been barred from the classroom. The court decided that the teacher, although handicapped by AIDS, most likely "is otherwise qualified to perform his job within the meaning of the Rehabilitation Act of 1973."

11/ 662 F. Supp. 376 (C.D.Calif. 1987)
12/ Chalk vs. U.S. District Court Central District of California, No. 87-6418 (9th Cir. November 18, 1987).

P.L. 94-142 could also be used as a basis for requiring the education of an HIV-infected child. This Act provides federal funds to the states and conditions the receipt of these funds on the provision of a "free appropriate public education." It would appear that the Act would cover some HIV-positive children. Madeleine Will, the Assistant Secretary for Special Education and Rehabilitative Services, has indicated that "[c]hildren with AIDS would be eligible for coverage under EHA-B if they are evaluated as having one of the handicapping conditions listed in the statute, and in need of special education and related services. Children with AIDS could be eligible for special education programs under the category of 'other health impaired.'"[13/]

B. CONTINUING ETHICAL DILEMMAS

Legal issues in the context of HIV-infected children deal with what the present protections and requirements are; ethical issues deal with how society should deal with the issues presented by these children. The two types of issues are related but distinct. This section will not attempt to solve the thorny ethical dilemmas but will simply note several areas where ethical considerations have arisen or may arise.

The basic ethical dilemma involving HIV-positive children is the balance between the rights of the children and of society in general. The tension between these groups could take several forms. There could be ethical questions concerning

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13/ 221 EHLR 343 (1984). Not all children with AIDS would necessarily be considered to fall within the definition of "other health-impaired." For example, see District 27, supra, at 13; Case No. 85-20 (August 26, 1985), 507 EHLR 303. But see Case No. 225, In re Ryan White (Feb. 14, 1986), 507 EHLR 342, where the student was found to have a handicapping condition.

the balancing between possible rights of HIV-positive children HIV-positive children and possible infection or danger to society, e.g., to others in school or in out-of-home placements. As was discussed above, the Supreme Court's analysis in Arline attempts to strike a balance relating to rights of persons with contagious diseases and the protection of society in its analysis of who is otherwise qualified.

Ethical questions could also be posed concerning the use of limited societal resources to educate or treat HIV-infected children who have a limited life expectancy and whose treatment is very costly. To what extent, if at all, should a cost-benefit analysis be used in situations involving an individual's rights, particularly rights to medical treatment or education?

Also, a tension between the parent's or guardian's interests and that of a child could arise regarding an HIV-infected child. To what extent should a parent or guardian be able to determine the type of medical care, experimental medical care, or even access to testing?

Although these and other ethical issues are not capable of easy resolution, their consideration is crucial in making determinations regarding HIV-infected children.

IV. THE FEDERAL EFFORT

A. LITTLE FOCUS AND FEW RESOURCES DEVOTED TO AIDS PREVENTION AND TREATMENT FOR CHILDREN AND YOUTH

While children and youth will benefit from overall federal spending for AIDS research, prevention and treatment, few efforts have been targeted specifically toward children so far. In Fiscal Year 1981, the total amount of federal funding dedicated to AIDS research and education was $200,000; by FY 1987 the figure was $494 million. The Administration's revised FY 1988 budget request for AIDS related activities was $791 million.

CDC has two programs dedicated to prevention of AIDS among children. For FY 1987, the CDC allocated $11.3 million to a "School Health Initiative." Of this amount, $6.5 million was obligated in FY 1987 to national education and child-serving organizations, and state and local school districts to disseminate information concerning AIDS and children, and to other agencies involved in developing training and demonstration projects. The CDC utilized the remaining funds for "direct operations," including contracts on materials developed for the CDC, evaluation, staff support, and outside consultation.

The CDC also provided an initial $24 million in FY 1987 to fund AIDS prevention efforts through community-based organizations. In early July 1987, an additional $27 million was added to this amount. Prevention activities conducted with these resources, while not targeted specifically to children, if successful could affect children positively, by reaching them

directly or by reaching at-risk adults who are or might become parents.

In FY 1987, $7.6 million of the National Institute of Health's $252 million AIDS research budget was dedicated to research specifically on childhood AIDS. Of this amount, $7.45 million was targeted to pediatric AIDS, and $152,000 to adolescents. Sixteen million of the Administration's FY 1988 request of $422 million for AIDS research would be focused specifically on children ($15.97 million for pediatric AIDS, $491,000 for adolescents).14/

CDC published statistics three and one-half years ago showing that blacks and Hispanics have substantially higher rates of AIDS compared to the total population. However, not until July 1987, were any funds targeted toward minority populations. At that time, Congress specified that $7 million of the $27 million FY 1987 supplemental appropriation be made available for prevention efforts specifically targeted toward minorities. As noted early in this report, nearly 80% of all the children with active AIDS are black or Hispanic, and more than 70% of all women with AIDS are members of a minority group.

Insufficient Funding for Children's Medical and Related Services

INADEQUATE SUPPORT FOR DIRECT MEDICAL SERVICES FOR INFANTS, CHILDREN AND ADOLESCENTS WITH AIDS LEAVES MAJOR GAPS IN TREATMENT

The primary way in which the federal government pays for medical services for children and adolescents with AIDS is

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14/ Revised request, June 30, 1987.

through Medicaid.[15/] Officials of the Health Care Financing Administration within the U.S. Department of Health and Human Services have estimated that Medicaid spending for the treatment of AIDS in the whole population will increase sixfold by FY 1992, increasing from $400 million this year to $2.4 billion. Of this amount, the federal government would pay about 55%. (71)

According to Oleske, the federal contribution toward paying for medical treatment of children and youth with AIDS is very far from adequate. Oleske told the Committee:

> ...there is little or no funding for these issues. Children receive very, very little of the monies allocated to AIDS work. Most of the money goes to research. Very, very little for care and treatment. (45)

He added:

> I guess one thing AIDS has taught me, besides a lot of humility in the frustration of not being able to treat people, was that as a country, I guess we do not know how to respond to an epidemic. Our agencies, the NIH and the CDC, and in a small way, the Federal Drug Administration, the FDA, are really not geared to handle a problem that is emergent and rapidly progressing. (45)

To address some of these financing problems, Heagarty in New York City recommended automatic access to some form of third party insurance, probably Medicaid, for children diagnosed with AIDS.

In addition, several recommendations concerning financing emerged from the Surgeon General's Workshop on Children with

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15/ Medicaid, authorized by Title XIX of the Social Security Act, is a federal-state matching program providing medical assistance for certain low-income persons who are aged, blind, disabled, or members of families with dependent children. The federal government's share of Medicaid is tied to a formula which is inversely related to the per capita income of the states, and averages 55%.

HIV Infection and Their Families in spring 1987:

(1) Because reliable data are scarce, we can make only rough estimates of the health care costs of pediatric HIV infection...a number of studies has found hospital utilization of 30 to 40 days per year per child....We estimate that by 1991 between 800 and 1,000 beds, representing 2% of the nation's pediatric beds, may be needed....The care must be multidisciplinary and must involve thorough coordination across a wide range of services and settings.

(2) Financing strategies must be designed to support and encourage alternatives to hospital care whenever possible. E.g., New Jersey is the first State to develop a "Home and Community Based Services Model Waiver for Persons with AIDS/ARC" under the Medicaid program...bringing Federal matching dollars into the State for multidisciplinary services not normally covered under Medicaid. In New York State, designated AIDS Care Centers receive an increased reimbursement rate for enhanced care to AIDS patients....Some of these facilities include specific pediatric AIDS services providing family support and linkages with community programs.

(3) ....All segments of the health care financing system should share the cost of HIV-related illness.

(4) Legislation should be supported which would waive the 24-month disability waiting period for Medicare eligibility for patients with AIDS who often do not live long enough to qualify.

(5) Federal government should add critically needed services to the minimum benefits which States are required to provide. Specifically, approved drugs, foster care, and home nursing care should be required of all States under Medicaid, with matching Federal funds. The Medicaid waiver program should be expanded to all States, along the lines of the New Jersey pilot program. The private sector should be encouraged to join these waiver programs by contributing funds for the development of case management and out-patient services and by developing innovative coverage strategies.

(6) Income eligibility requirements for Medicaid should be altered to allow coverage of families who are working poor or uninsured. (68)

The evolving nature of the AIDS epidemic among young children and adolescents will require thoughtful consideration of these and other financing strategies for research and treatment, if we are to halt the spread of the AIDS virus and offer appropriate and humane care to all who may be affected.

Also Little Legislative Action Regarding Children and AIDS

While more than four dozen legislative proposals have been introduced on the AIDS epidemic, only six address the emerging special needs of children and youth.

One proposal in the House of Representatives and one in the Senate have as their main thrust to waive the 2-year waiting period for Medicare eligibility for individuals disabled by AIDS.16/ The Senate proposal includes a requirement for the Secretary of Health and Human Services to conduct a survey on children with AIDS who lack parental involvement and support or who have been placed in foster care. This Senate proposal was contained in the Senate's Budget Reconciliation bill.

Two bills -- one pending in the House, the other in the Senate -- propose amending the Public Health Service Act to provide a comprehensive program of AIDS education, information, risk reduction, training, prevention, treatment, care and research. 17/

There are also Senate and House proposals to address the problems of infants exposed to drugs or to HIV infection who may be abandoned in hospitals -- the so-called "boarder babies" discussed earlier in this report. The Senate passed the bill

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16/ S. 24, A bill to amend title II of the Social Security to waive, for 5 years, the 24-month waiting period for Medicare eligibility on the basis of a disability in the cases of individuals with AIDS.
H.R. 276, Companion bill to S. 24 in the House of Representatives.

17/ S. 1220, A bill to amend the Public Health Service Act to provide for a comprehensive program of education, information, risk reduction, training, prevention, treatment, care, and research concerning AIDS.
H.R. 2626, Companion bill to S. 1220 in the House of Representatives.

in August; the measure is pending in the House. 18/

B. OVERALL, FEDERAL RESPONSE TO THE AIDS EPIDEMIC FOUND LACKING IN FUNDING AND LEADERSHIP

The AIDS epidemic has fueled numerous calls for bold, coordinated action to stem the spread of HIV infection among the population and to enable our health, education and social service systems to respond adequately and humanely.

Despite the fact that no vaccine or cure may be available for years, experts agree that research has made dramatic strides in understanding the disease and the virus. In contrast, unfortunately, experts also agree that still little has been done by the federal government in delivering AIDS information and education -- the only protection currently available to prevent the spread of the virus.

More than a year ago, the Institute of Medicine (IOM) of the National Academy of Sciences said that AIDS education should be "pursued with a sense of urgency and a level of funding appropriate for a life-or-death situation." The IOM report noted that

> For at least the next several years, the most effective measure for significantly reducing the spread of HIV infection is education of the public, especially those individuals at higher risk....The present federal effort is woefully inadequate in terms of both the amount of educational material made available and its clear communication of intended messages. (32)

18/ S. 945, "Abandoned Infants Assistance Act of 1987." H.R. 3009, Companion bill to S. 945.

This year, October 1987 was declared National AIDS Awareness Month. At the beginning of the month, the Centers for Disease Control began a nationwide AIDS information and prevention campaign, the goal of which is "to reach every American citizen with the facts about AIDS." The campaign includes public service announcements, print ads, brochures and other materials, and special informational programs to provide opportunities for discussions about AIDS.

Also in October 1987, the Department of Education issued a handbook entitled "AIDS and the Education of our Children," to be distributed to principals, school boards, parents' groups and other educators.

Mervyn Silverman, President of the American Foundation for AIDS Research and Director of the Robert Wood Johnson AIDS Health Services Program, in testimony before the Ad Hoc Task Force on AIDS of the House Budget Committee, highlighted disturbing evidence that, notwithstanding the federal education campaign, very little had changed since the IOM report in 1986. He testified that:

- The CDC has just this year decided to launch a national information campaign about AIDS, 6 years after the disease was first reported.
- Requests to obtain copies of the Surgeon General's report on AIDS, perhaps the most thorough and effective brochure yet produced, seem to fall on deaf ears. We at AMFAR have waited 5 months for delivery of a mere one thousand copies.
- Little or nothing has been accomplished in streamlining the paperwork required for federal funding for education. Health educators often spend more time completing paperwork than educating. (54)

Further, an August 1987 General Accounting Office review of AIDS prevention and the Administration's proposed 1988 budget

reported a consensus of experts that federal efforts so far have been underfunded, uncoordinated, and insufficient.

Experts at the national, state and local levels generally concurred with priorities for action reflected in the budget proposals, which focused on "1) reducing HIV infection among IV drug users and their sexual partners, 2) educating targeted high-risk groups and the general public, and 3) expanding the availability of voluntary testing with pretest and posttest counseling." (61)

However, these public health authorities and medical experts surveyed by the GAO said that the "resources are inadequate in all priority areas...and that at least $365 million more is needed for AIDS prevention programs." (61)

GAO further emphasized the need to expand voluntary testing and counseling services:

> HHS estimates that the revised federal budget provides funds for about half the counseling and testing needed nationwide. Using an average cost per test of $45, we estimate the federal budget matched with state funds would cover testing and counseling services for about 4 million individuals. According to IOM's report, however, more than 10 million persons may be candidates for testing. Recent CDC data on the estimated populations at high risk of HIV infection...approach 10 million persons. At an average cost of $45 per person, potential resources needed if these individuals request testing would approach $450 million. Assuming federal and state resources of about $184 million, over $250 million more in funding would be needed to meet this demand. (61)

Experts surveyed also expressed serious dismay about the lack of federal leadership, considered "at least as troublesome as shortfalls in the budget." (61) A related problem cited was the "piecemeal nature of federal, state, and local funding

and the administrative requirements for obtaining such funds."

Concerns regarding federal leadership have persisted with continuing turmoil surrounding the Presidential Commission on the Human Immunodeficiency Virus Epidemic. The Commission, appointed in July 1987, first came under attack on the grounds that its membership lacked the necessary expertise on AIDS, as well as the objectivity to fulfill its mission to advise the federal government regarding AIDS prevention and treatment. In September, the Commission's executive director of only a few months was forced to resign. In early October, the chairman and vice chairman of the Commission resigned, citing ideological differences and lack of support from the Administration that reportedly undercut their ability to do their jobs. And, in mid-October, a coalition of civil rights and public health groups filed a lawsuit against the Commission, charging that a lack of balance in the groups and viewpoints represented among Commission members violates the Federal Advisory Committee Act.

Undetectable "War on Drugs" Threatens AIDS Efforts

After promoting a "War on Drugs" and signing legislation authorizing $1.7 billion in new funds under the Anti-Drug Abuse Act of 1986, the Administration proposed cutting funding for treatment, education and law enforcement in FY 1988.

Highlighting the need for more funds to limit the spread of HIV among IV drug users and their partners (whose infants and young children account for 73% of the children under 13 with pediatric AIDS), the GAO noted that the "availability of treatment for IV drug users was less than demand even before the AIDS epidemic." (61) Officials in New York City, which

has about one-third of the country's IV drug users, reported that IV drug users may wait for up to two months for treatment.

It is estimated that of the Nation's 500,000 to 1.2 million of the nation's IV drug abusers -- those at high risk of becoming infected with and transmitting the AIDS virus -- only about 10% receive drug treatment. As noted earlier, in New York City, the major epicenter of the epidemic so far, health officials reported a study of all drug-related deaths in the City from 1982-1986 found that AIDS-related deaths among intravenous drug users surpassed those among homosexual and bisexual men during that period. Intravenous drug users accounted for 53% of all AIDS-related deaths, while deaths involving sexually active homosexual and bisexual men accounted for 38%. (3)

In addition to already inadequate treatment resources and continuing shortfalls, the drug education effort, a principal tool in stemming the spread of AIDS particularly among children and youth, was also proposed to be cut in half.

APPENDIX I

REFERENCES

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REFERENCES

1. "Abused Children in America: Victims of Official Neglect," A Report of the Select Committee on Children, Youth and Families, U.S. House of Representatives, Washington, D.C., March 1987.

2. Adler, Becky, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

3. "AIDS in New York City Killing More Drug Users," The New York Times, October 22, 1987.

4. Alan Guttmacher Institute, "United States and Cross-National Trends in Teenage Sexuality and Fertility Behavior," New York, Unpublished data, 1986.

5. Aledort, Louis M., Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families," U.S. House of Representatives, Washington, D.C., June 18, 1987.

6. American Academy of Pediatrics, Committee on Infectious Diseases, "Health Guidelines for the Attendance in Day Care and Foster Care Settings of Children Infected With Human Immunodeficiency Virus," Pediatrics, Vol. 79, No. 3, March 1987.

7. American Academy of Pediatrics, Committee on School Health, Committee on Infectious Diseases, "School Attendance of Children and Adolescents with Human T Lymphotropic Virus III/Lymphadenopathy - Associated Virus Infection," Pediatrics, Vol. 77, No. 3, March 1986.

8. Anderson, Virginia, Testimony before the Subcommittee on Select Education, Committee on Education and Labor, U.S. House of Representatives, Washington, D.C., October 22, 1987.

9. Barrick, William, Testimony at Hearing, "AIDS and Young Children: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Berkeley, California, February 21, 1987.

10. Benjamin, Robert, Testimony at Hearing, "AIDS and Young Children: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Berkeley, California, February 21, 1987.

11. "Bleak Lives: Women Carrying AIDS," The New York Times, August 27, 1987.

12. Burke, Donald S., Personal Communication, July 1987.

13. Burke, Donald S., et al, "Human Immunodeficiency Virus Infection Among Civilian Applicants for United States Military Services, October 1985 to March 1986, New England Journal of Medicine, 1987, Vol., 317, No. 3, 133-136.

14. Butynski, William, and Canova, Diane, National Association of State Alcohol and Drug Abuse Directors, Personal Communication, October 1987.

15. Citizens Committee for Children of New York, Inc., The Invisible Emergency: Children and AIDS in New York, April 1987, p. 10.

16. Davidson, Joe, "Medicaid Spending on AIDS to Increase Sixfold by 1992, Health Officials Say," The Wall Street Journal, September 10, 1987.

17. DiClemente, Ralph J., et al, "Adolescents and AIDS: A Survey of Knowledge, Attitudes and Beliefs about AIDS in San Francisco," American Journal of Public Health, 1986, Vol. 76, No. 12, 1443-1445.

18. "Drug Treatment Shortage Imperils AIDS Control," The New York Times, October 4, 1987.

19. English, Abigail, "Ethical/Legal Aspects of AIDS and STDS in Adolescents," Gallagher Lecture, Society for Adolescent Medicine, March 21, 1987.

20. Fagan, Tricia, Testimony at Hearing, "The Crisis in Homelessness: Effects on Children and Families," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., February 24, 1987.

21. Ginsburg, Harold, "Legal Issues Surrounding Medical Care, Treatment, and Research of Children," Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, U.S. Department of Health and Human Services, Public Health Service, April 1987.

22. Gordon, Richard, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

23. Grossman, Moses, Testimony at Hearing, "AIDS and Young Children: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Berkeley, CA, February 21, 1987.

24. Gurdin, Phyllis and Anderson, Gary R., "Quality Care for Ill Children: AIDS-Specialized Foster Family Homes," Child Welfare, Vol. LXVI, No. 4, July/August 1987.

25. Hale, Lorraine, Testimony before the Select Committee on Narcotics Abuse and Control, U.S. House of Representatives, New York, N.Y., July 27, 1987.

26. Hamilton, Johnnie, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

27. Heagarty, Margaret, Testimony before the Select Committee on Narcotics Abuse and Control, U.S. House of Representatives, Washington, D.C., July 27, 1987.

28. Hein, Karen, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

29. Hein, Karen, Personal Communication, November 1987.

30. Hooper, Susan, "AIDS and the Public Schools," National School Boards Association Leadership Report, Alexandria, VA, Volume 1, 1986.

31. Howe, Jonathan, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

32. Institute of Medicine, National Academy of Sciences, Confronting AIDS: Directions for Public Health, Health Care, and Research, Washington: National Academy Press, 1986.

33. Koop, C. Everett, Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, U.S. Department of Health and Human Services, Public Health Service, 1987.

34. Koop, C. Everett, Testimony before the Select Committee on Narcotics Abuse and Control, U.S. House of Representatives, New York, N.Y., July 27, 1987.

35. Koop, C. Everett, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

36. Lipsitz, Joan, Testimony at Hearing, "Teenagers in Crisis: Issues and Programs," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington D.C., October 27, 1983.

37. Lutton, Wayne, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

38. Mark, Vernon, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., June 18, 1987.

39. Merlis, Mark, Congressional Research Service, Library of Congress, Personal Communication, October 1987.

40. McIntosh, Jean, Testimony at Hearing, "AIDS and Young Children: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., February 21, 1987.

41. Murphy, Solbrit, Division of Family Health, New York State, Personal Communication, August 1987.

42. National Association of State Boards of Education, "NASBE Releases AIDS Survey," June 9, 1987.

43. National Commission to Prevent Infant Mortality, "Perinatal AIDS," Washington, D.C., October 1987.

44. New York City Health and Hospital Corporation, November 1986.

45. Oleske, James, Testimony at hearing, "Placing Infants at Risk: Parental Addiction and Disease," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Washington, D.C., May 21, 1986.

46. Oleske, James, "Natural History of HIV Infection II," Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, U.S. Department of Health and Human Services, Public Health Service, 1987.

47. Oleske, James, Personal Communication, November 1987.

48. Pressma, Donna, Testimony of the Child Welfare League of America before the Subcommittee on Select Education, Committee on Education and Labor, U.S. House of Representatives, October 22, 1987.

49. Quackenbush, Marcia, Testimony at Hearing, "AIDS and Young Children: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Berkeley, CA, February 21, 1987.

50. Rogers, Martha F., "Transmission of Human Immunodeficiency Virus Infection in the United States," Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, U.S. Department of Health and Human Services, Public Health Service, April 1987.

51. Scott, Gwendolyn B., "Natural History of HIV Infection in Children," Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, U.S. Department of Health and Human Services, Public Health Service, April 1987.

52. Shafer, Mary-Ann, Testimony at Hearing, "AIDS and Teenagers: Emerging Issues," Select Committee on Children, Youth, and Families, June 18, 1987.

53. Sheridan, Tom, Child Welfare League of America, Personal Communication, November 1987.

54. Silverman, Mervyn, Testimony before Ad Hoc Task Force on AIDS of the Committee on Budget, U.S. House of Representatives, Washington, D.C., October 8, 1987.

55. Sitovsky, Anne A. and Rice, Dorothy P., "Estimates of the Direct and Indirect Costs of Acquired Immunodeficiency Syndrome in the United States, 1985, 1986, and 1991," Public Health Reports, January-February 1987, Vol. 102, No. 1, 5-17.

56. State of New Jersey, Department of Health, "AIDS in New Jersey, A Report from the Department of Health," April 1987.

57. Stephan, Sharon, "Child Welfare, Foster Care, and Related Programs under Titles IV-B and IV-E of the Social Security Act," Library of Congress, Congressional Research Service, April 1987.

58. "The Most Tragic Victims of AIDS: Thousands of Youngsters," The New York Times, July 17, 1987.

59. Thomas, Joyce, Testimony at Hearing, "Placing Infants at Risk: Parental Addiction and Disease," Select Committee on Children, Youth, and Families, Washington, D.C., May 21, 1986.

60. U.S. Department of Education, "AIDS and the Education of Our Children, A Guide for Parents and Teachers," October 1987.

61. U.S. General Accounting Office, "AIDS Prevention: Views on the Administration's Budget Proposals," August 1987, HRD-87-126BR.

62. U.S. Department of Health and Human Services, Center for Disease Control, "Aids Weekly Surveillance Report -- United States AIDS Program," November 30, 1987.

63. U.S. Department of Health and Human Services, Fiscal Year 1985 Study of Runaways and Youth, Washington, D.C., 1986.

64. "U.S. Drug 'Crusade' Is Seen As Undermining Itself," The New York Times, October 26, 1987.

65. Villarreal, Sylvia, Testimony at Hearing, "AIDS and Young Children: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Berkeley, CA, February 21, 1987.

66. William, Mary Kaye, and Jones, Judith Miller, "Children With AIDS: Education, Health, and Prevention Issues," National Health Policy Forum, Issue Brief No. 463, the George Washington University, April 1987.

67. Williams, John, Testimony at Hearing, "AIDS and Young Children: Emerging Issues," Select Committee on Children, Youth, and Families, U.S. House of Representatives, Berkeley, CA, February 21, 1987.

68. "Work Group IX: Financial Issues in the Care of Children with HIV Infection," Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, U.S. Department of Health and Human Services, Public Health Service, April 1987.

69. "Drugs Impact Is Seen Rising Among Poor," The New York Times, August 30, 1987.

70. U.S. Department of Health and Human Service, Child Welfare Statistical Fact Book 1984: Substitute Care/ Adoption, August 1986.

71. "Medical Spending on AIDS to Increase Sixfold by 1992, Health Office Says," The Wall Street Journal, September 10, 1987.

72. Communication from meeting with Joyce Hunter, Director of Social Services IPLGY, New York, N.Y. and Gabe Kruks, Director of Youth Services at the Center in Los Angeles, CA, and Tom Sheridan, Child Welfare League of America, Washington, D.C., September 1987.

73. "AIDS Threat Brings New Turmoil for Gay Teenagers," The New York Times, October 21, 1987

74. Alan Guttmacher Institute, "United States and Cross National Trends in Teenage Sexuality and Fertility Behavior," Unpublished data, 1986.

75. "Teen-Age Pregnancy and Birth Rate Drop," The New York Times, October 20, 1987

76. Stehr-Green, Jeannette, Centers for Disease Control, Personal Communication, November 1987.

77. Hilgartner, Margaret W., "HIV Transmitted by Blood Products," Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, U.S. Department of Health and Human Services, Public Health Service, April 1987.

78. Chollet, Deborah, Employee Benefit Research Institute, Personal Communication, July 1987.

79. National Center for Health Statistics, "Medical Care Utilization and Expenditure Survey," Unpublished data, presented by Kovar, Mary Grace, Health Futures of Adolescents, National Invitational Conference, April 1986.

80. "Surgeon General's Report on Acquired Immune Deficiency Syndrome," U.S. Department of Health and Human Services, Public Health Service, October 1986.

81. "Surgeon General Koop: The Right, the Left and the Center of the AIDS Storm," The Washington Post, Health, Science and Society, March 24, 1987.

82. "Pace of Heterosexual AIDS Spread Surprise Scientists," The Washington Post, Health, Science and Society, October 6, 1987.

83. Congressional Research Service in October provided updated figures from the National Association of State Boards of Education regarding the Association's state survey of mandated AIDS education. Preliminary survey issued in June 1987.

84. National Association of State Boards of Education, State-by-State Survey on AIDS Education. Alexandria, VA, December 2, 1987.

APPENDIX II

CENTER FOR DISEASE CONTROL GUIDELINES

CENTERS FOR DISEASE CONTROL

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MMWR

Supplement

MORBIDITY AND MORTALITY WEEKLY REPORT

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Centers for Disease Control ..... James O. Mason, M.D., Dr.P.H.
Director

Center for Infectious Diseases ..... Frederick A. Murphy, D.V.M., Ph.D.
Acting Director

AIDS Program ..... James W. Curran, M.D.
Director

This report was prepared by:

Epidemiology Program Office ..... Carl W. Tyler, Jr., M.D.
Director

Michael B. Gregg, M.D.
Editor, MMWR

Editorial Services ..... R. Elliott Churchill, M.A.
Chief

Ruth Greenberg
Editorial Assistant

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Reported by
Council of State and Territorial Epidemiologists;
AIDS Program, Center for Infectious Diseases, CDC

INTRODUCTION

The following revised case definition for surveillance of acquired immunodeficiency syndrome (AIDS) was developed by CDC in collaboration with public health and clinical specialists. The Council of State and Territorial Epidemiologists (CSTE) has officially recommended adoption of the revised definition for national reporting of AIDS. The objectives of the revision are a) to track more effectively the severe disabling morbidity associated with infection with human immunodeficiency virus (HIV) (including HIV-1 and HIV-2); b) to simplify reporting of AIDS cases; c) to increase the sensitivity and specificity of the definition through greater diagnostic application of laboratory evidence for HIV infection; and d) to be consistent with current diagnostic practice, which in some cases includes presumptive, i.e., without confirmatory laboratory evidence, diagnosis of AIDS-indicative diseases (e.g., *Pneumocystis carinii* pneumonia, Kaposi's sarcoma).

The definition is organized into three sections that depend on the status of laboratory evidence of HIV infection (e.g., HIV antibody) (Figure 1). The major proposed changes apply to patients with laboratory evidence for HIV infection: a) inclusion of HIV encephalopathy, HIV wasting syndrome, and a broader range of specific AIDS-indicative diseases (Section II.A); b) inclusion of AIDS patients whose indicator diseases are diagnosed presumptively (Section II.B); and c) elimination of exclusions due to other causes of immunodeficiency (Section I.A).

Application of the definition for children differs from that for adults in two ways. First, multiple or recurrent serious bacterial infections and lymphoid interstitial pneumonia/pulmonary lymphoid hyperplasia are accepted as indicative of AIDS among children but not among adults. Second, for children<15 months of age whose mothers are thought to have had HIV infection during the child's perinatal period, the laboratory criteria for HIV infection are more stringent, since the presence of HIV antibody in the child is, by itself, insufficient evidence for HIV infection because of the persistence of passively acquired maternal antibodies < 15 months after birth.

The new definition is effective immediately. State and local health departments are requested to apply the new definition henceforth to patients reported to them. The initiation of the actual reporting of cases that meet the new definition is targeted for September 1, 1987, when modified computer software and report forms should be in place to accommodate the changes. CSTE has recommended retrospective application of the revised definition to patients already reported to health departments. The new definition follows:

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1987 REVISION OF CASE DEFINITION FOR AIDS FOR SURVEILLANCE PURPOSES

For national reporting, a case of AIDS is defined as an illness characterized by one or more of the following "indicator" diseases, depending on the status of laboratory evidence of HIV infection, as shown below.

I. Without Laboratory Evidence Regarding HIV Infection

If laboratory tests for HIV were not performed or gave inconclusive results (*See* Appendix I) and the patient had no other cause of immunodeficiency listed in Section I.A below, then any disease listed in Section I.B indicates AIDS if it was diagnosed by a definitive method (*See* Appendix II).

A. Causes of immunodeficiency that disqualify diseases as indicators of AIDS in the absence of laboratory evidence for HIV infection

1. high-dose or long-term systemic corticosteroid therapy or other immunosuppressive/cytotoxic therapy ≤3 months before the onset of the indicator disease
2. any of the following diseases diagnosed ≤3 months after diagnosis of the indicator disease: Hodgkin's disease, non-Hodgkin's lymphoma (other than primary brain lymphoma), lymphocytic leukemia, multiple myeloma, any other cancer of lymphoreticular or histiocytic tissue, or angioimmunoblastic lymphadenopathy
3. a genetic (congenital) immunodeficiency syndrome or an acquired immunodeficiency syndrome atypical of HIV infection, such as one involving hypogammaglobulinemia

B. Indicator diseases diagnosed definitively (*See* Appendix II)

1. candidiasis of the esophagus, trachea, bronchi, or lungs
2. cryptococcosis, extrapulmonary
3. cryptosporidiosis with diarrhea persisting >1 month
4. cytomegalovirus disease of an organ other than liver, spleen, or lymph nodes in a patient >1 month of age
5. herpes simplex virus infection causing a mucocutaneous ulcer that persists longer than 1 month; or bronchitis, pneumonitis, or esophagitis for any duration affecting a patient >1 month of age
6. Kaposi's sarcoma affecting a patient < 60 years of age
7. lymphoma of the brain (primary) affecting a patient < 60 years of age
8. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child <13 years of age
9. *Mycobacterium avium* complex or *M. kansasii* disease, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. *Pneumocystis carinii* pneumonia
11. progressive multifocal leukoencephalopathy
12. toxoplasmosis of the brain affecting a patient >1 month of age

II. With Laboratory Evidence for HIV Infection

Regardless of the presence of other causes of immunodeficiency (I.A), in the presence of laboratory evidence for HIV infection (*See* Appendix I), any disease listed above (I.B) or below (II.A or II.B) indicates a diagnosis of AIDS.

A. Indicator diseases diagnosed definitively (*See* Appendix II)

1. bacterial infections, multiple or recurrent (any combination of at least two within a 2-year period), of the following types affecting a child < 13 years of age:

   septicemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity (excluding otitis media or superficial skin or mucosal abscesses), caused by *Haemophilus*, *Streptococcus* (including pneumococcus), or other pyogenic bacteria
2. coccidioidomycosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
3. HIV encephalopathy (also called "HIV dementia," "AIDS dementia," or "subacute encephalitis due to HIV") (*See* Appendix II for description)
4. histoplasmosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
5. isosporiasis with diarrhea persisting >1 month
6. Kaposi's sarcoma at any age
7. lymphoma of the brain (primary) at any age
8. other non-Hodgkin's lymphoma of B-cell or unknown immunologic phenotype and the following histologic types:
   a. small noncleaved lymphoma (either Burkitt or non-Burkitt type) (*See* Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases*, Ninth Revision, Clinical Modification)
   b. immunoblastic sarcoma (equivalent to any of the following, although not necessarily all in combination: immunoblastic lymphoma, large-cell lymphoma, diffuse histiocytic lymphoma, diffuse undifferentiated lymphoma, or high-grade lymphoma) (*See* Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases*, Ninth Revision, Clinical Modification)

   Note: Lymphomas are not included here if they are of T-cell immunologic phenotype or their histologic type is not described or is described as "lymphocytic," "lymphoblastic," "small cleaved," or "plasmacytoid lymphocytic"
9. any mycobacterial disease caused by mycobacteria other than *M. tuberculosis*, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. disease caused by *M. tuberculosis*, extrapulmonary (involving at least one site outside the lungs, regardless of whether there is concurrent pulmonary involvement)
11. *Salmonella* (nontyphoid) septicemia, recurrent
12. HIV wasting syndrome (emaciation, "slim disease") (*See* Appendix II for description)

B. Indicator diseases diagnosed presumptively (by a method other than those in Appendix II)

Note: Given the seriousness of diseases indicative of AIDS, it is generally important to diagnose them definitively, especially when therapy that would be used may have serious side effects or when definitive diagnosis is needed

for eligibility for antiretroviral therapy. Nonetheless, in some situations, a patient's condition will not permit the performance of definitive tests. In other situations, accepted clinical practice may be to diagnose presumptively based on the presence of characteristic clinical and laboratory abnormalities. Guidelines for presumptive diagnoses are suggested in Appendix III.

1. candidiasis of the esophagus
2. cytomegalovirus retinitis with loss of vision
3. Kaposi's sarcoma
4. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child <13 years of age
5. mycobacterial disease (acid-fast bacilli with species not identified by culture), disseminated (involving at least one site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
6. *Pneumocystis carinii* pneumonia
7. toxoplasmosis of the brain affecting a patient >1 month of age

III. With Laboratory Evidence Against HIV Infection

With laboratory test results negative for HIV infection (*See* Appendix I), a diagnosis of AIDS for surveillance purposes is ruled out *unless*:

A. all the other causes of immunodeficiency listed above in Section I.A are excluded; **AND**

B. the patient has had either:

1. *Pneumocystis carinii* pneumonia diagnosed by a definitive method (*See* Appendix II); **OR**
2. a. any of the other diseases indicative of AIDS listed above in Section I.B diagnosed by a definitive method (*See* Appendix II); **AND**
   b. a T-helper/inducer (CD4) lymphocyte count <400/mm^3.

COMMENTARY

The surveillance of severe disease associated with HIV infection remains an essential, though not the only, indicator of the course of the HIV epidemic. The number of AIDS cases and the relative distribution of cases by demographic, geographic, and behavioral risk variables are the oldest indices of the epidemic, which began in 1981 and for which data are available retrospectively back to 1978. The original surveillance case definition, based on then-available knowledge, provided useful epidemiologic data on severe HIV disease (*1*). To ensure a reasonable predictive value for underlying immunodeficiency caused by what was then an unknown agent, the indicators of AIDS in the old case definition were restricted to particular opportunistic diseases diagnosed by reliable methods in patients without specific known causes of immunodeficiency. After HIV was discovered to be the cause of AIDS, however, and highly sensitive and specific HIV-antibody tests became available, the spectrum of manifestations of HIV infection became better defined, and classification systems for HIV infection were developed (*2-5*). It became apparent that some progressive, seriously disabling, and even fatal conditions (e.g., encephalopathy, wasting syndrome) affecting a substantial number of HIV-infected patients were not subject to epidemiologic surveillance, as they were not included in the AIDS

case definition. For reporting purposes, the revision adds to the definition most of those severe non-infectious, non-cancerous HIV-associated conditions that are categorized in the CDC clinical classification systems for HIV infection among adults and children (*4,5*).

Another limitation of the old definition was that AIDS-indicative diseases are diagnosed presumptively (i.e., without confirmation by methods required by the old definition) in 10%-15% of patients diagnosed with such diseases; thus, an appreciable proportion of AIDS cases were missed for reporting purposes (*6,7*). This proportion may be increasing, which would compromise the old case definition's usefulness as a tool for monitoring trends. The revised case definition permits the reporting of these clinically diagnosed cases as long as there is laboratory evidence of HIV infection.

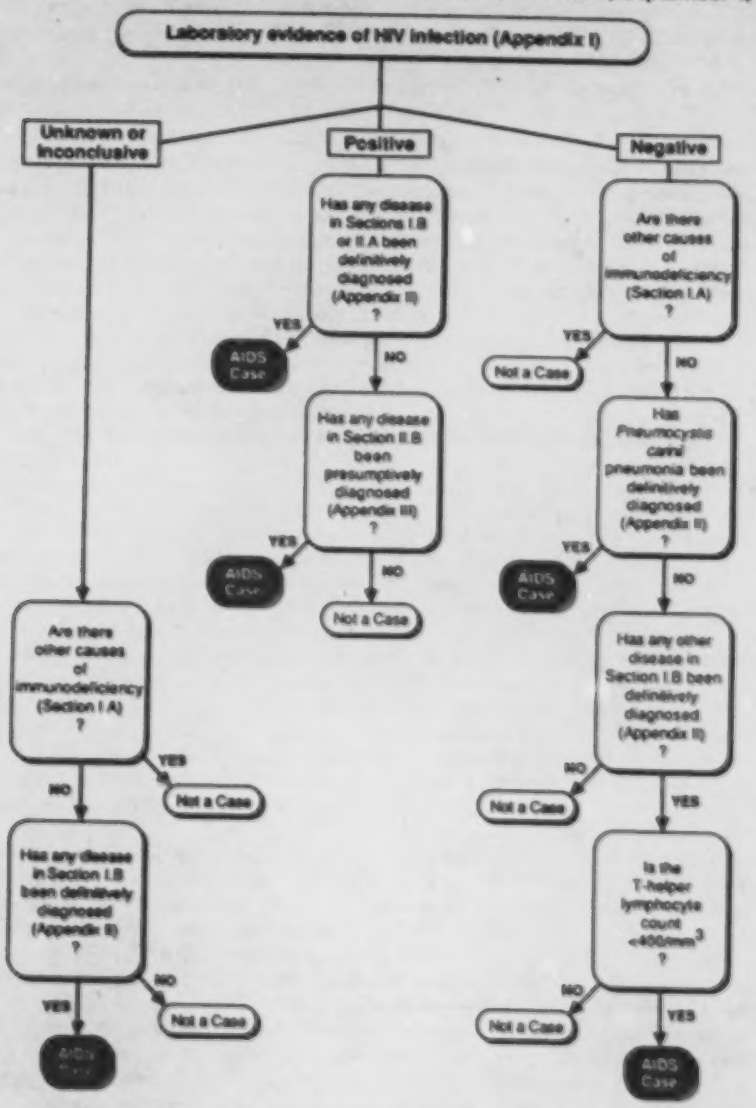
The effectiveness of the revision will depend on how extensively HIV-antibody tests are used. Approximately one third of AIDS patients in the United States have been from New York City and San Francisco, where, since 1985, < 7% have been reported with HIV-antibody test results, compared with > 60% in other areas. The impact of the revision on the reported numbers of AIDS cases will also depend on the proportion of AIDS patients in whom indicator diseases are diagnosed presumptively rather than definitively. The use of presumptive diagnostic criteria varies geographically, being more common in certain rural areas and in urban areas with many indigent AIDS patients.

To avoid confusion about what should be reported to health departments, the term "AIDS" should refer only to conditions meeting the surveillance definition. This definition is intended only to provide consistent statistical data for public health purposes. Clinicians will not rely on this definition alone to diagnose serious disease caused by HIV infection in individual patients because there may be additional information that would lead to a more accurate diagnosis. For example, patients who are not reportable under the definition because they have either a negative HIV-antibody test or, in the presence of HIV antibody, an opportunistic disease not listed in the definition as an indicator of AIDS nonetheless may be diagnosed as having serious HIV disease on consideration of other clinical or laboratory characteristics of HIV infection or a history of exposure to HIV.

Conversely, the AIDS surveillance definition may rarely misclassify other patients as having serious HIV disease if they have no HIV-antibody test but have an AIDS-indicative disease with a background incidence unrelated to HIV infection, such as cryptococcal meningitis.

The diagnostic criteria accepted by the AIDS surveillance case definition should not be interpreted as the standard of good medical practice. Presumptive diagnoses are accepted in the definition because not to count them would be to ignore substantial morbidity resulting from HIV infection. Likewise, the definition accepts a reactive screening test for HIV antibody without confirmation by a supplemental test because a repeatedly reactive screening test result, in combination with an indicator disease, is highly indicative of true HIV disease. For national surveillance purposes, the tiny proportion of possibly false-positive screening tests in persons with AIDS-indicative diseases is of little consequence. For the individual patient, however, a correct diagnosis is critically important. The use of supplemental tests is, therefore, strongly endorsed. An increase in the diagnostic use of HIV-antibody tests could improve both the quality of medical care and the function of the new case definition, as well as assist in providing counselling to prevent transmission of HIV.

FIGURE I. Flow diagram for revised CDC case definition of AIDS, September 1, 1987



References

1. World Health Organization. Acquired immunodeficiency syndrome (AIDS): WHO/CDC case definition for AIDS. WHO Wkly Epidemiol Rec 1986;61:69-72.
2. Haverkos HW, Gottlieb MS, Killen JY, Edelman R. Classification of HTLV-III/LAV-related diseases [Letter]. J Infect Dis 1985;152:1095.
3. Redfield RR, Wright DC, Tramont EC. The Walter Reed staging classification of HTLV-III infection. N Engl J Med 1986;314:131-2.
4. CDC. Classification system for human T-lymphotropic virus type III/lymphadenopathy-associated virus infections. MMWR 1986;35:334-9.
5. CDC. Classification system for human immunodeficiency virus (HIV) infection in children under 13 years of age. MMWR 1987;36:225-30,235.
6. Hardy AM, Starcher ET, Morgan WM, et al. Review of death certificates to assess completeness of AIDS case reporting. Pub Hlth Rep 1987;102(4):386-91.
7. Starcher ET, Biel JK, Rivera-Castano R, Day JM, Hopkins SG, Miller JW. The impact of presumptively diagnosed opportunistic infections and cancers on national reporting of AIDS [Abstract]. Washington, DC : III International Conference on AIDS, June 1-5, 1987.

APPENDIX I

Laboratory Evidence For or Against HIV Infection

1. **For Infection:**
   When a patient has disease consistent with AIDS:
   a. a serum specimen from a patient ≥15 months of age, or from a child <15 months of age whose mother is not thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., enzyme-linked immunosorbent assay [ELISA]), as long as subsequent HIV-antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; **OR**
   b. a serum specimen from a child < 15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., ELISA), plus increased serum immunoglobulin levels and at least one of the following abnormal immunologic test results: reduced absolute lymphocyte count, depressed CD4 (T-helper) lymphocyte count, or decreased CD4/CD8 (helper/suppressor) ratio, as long as subsequent antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; **OR**
   c. a positive test for HIV serum antigen; **OR**
   d. a positive HIV culture confirmed by both reverse transcriptase detection and a specific HIV-antigen test or in situ hybridization using a nucleic acid probe; **OR**
   e. a positive result on any other highly specific test for HIV (e.g., nucleic acid probe of peripheral blood lymphocytes).

2. **Against Infection:**
   A nonreactive screening test for serum antibody to HIV (e.g., ELISA) without a reactive or positive result on any other test for HIV infection (e.g., antibody, antigen, culture), if done.

3. **Inconclusive (Neither For nor Against Infection):**
   a. a repeatedly reactive screening test for serum antibody to HIV (e.g., ELISA) followed by a negative or inconclusive supplemental test (e.g., Western blot, immunofluorescence assay) without a positive HIV culture or serum antigen test, if done; **OR**
   b. a serum specimen from a child < 15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test, even if positive by a supplemental test, without additional evidence for immunodeficiency as described above (in 1.b) and without a positive HIV culture or serum antigen test, if done.

APPENDIX II

Definitive Diagnostic Methods for Diseases Indicative of AIDS

Diseases	Definitive Diagnostic Methods
cryptosporidiosis cytomegalovirus isosporiasis Kaposi's sarcoma lymphoma lymphoid pneumonia or hyperplasia *Pneumocystis carinii* pneumonia progressive multifocal leukoencephalopathy toxoplasmosis	microscopy (histology or cytology).
candidiasis	gross inspection by endoscopy or autopsy or by microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface), not from a culture.
coccidioidomycosis cryptococcosis herpes simplex virus histoplasmosis	microscopy (histology or cytology), culture, or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.
tuberculosis other mycobacteriosis salmonellosis other bacterial infection	culture.

HIV encephalopathy* (dementia)	clinical findings of disabling cognitive and/or motor dysfunction interfering with occupation or activities of daily living, or loss of behavioral developmental milestones affecting a child, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection that could explain the findings. Methods to rule out such concurrent illnesses and conditions must include cerebrospinal fluid examination and either brain imaging (computed tomography or magnetic resonance) or autopsy.
HIV wasting syndrome*	findings of profound involuntary weight loss >10% of baseline body weight plus either chronic diarrhea (at least two loose stools per day for ≥ 30 days) or chronic weakness and documented fever (for ≥ 30 days, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that could explain the findings (e.g., cancer, tuberculosis, cryptosporidiosis, or other specific enteritis).

*For HIV encephalopathy and HIV wasting syndrome, the methods of diagnosis described here are not truly definitive, but are sufficiently rigorous for surveillance purposes.

APPENDIX III

Suggested Guidelines for Presumptive Diagnosis of Diseases Indicative of AIDS

Diseases	Presumptive Diagnostic Criteria
candidiasis of esophagus	a. recent onset of retrosternal pain on swallowing; **AND** b. oral candidiasis diagnosed by the gross appearance of white patches or plaques on an erythematous base or by the microscopic appearance of fungal mycelial filaments in an uncultured specimen scraped from the oral mucosa.
cytomegalovirus retinitis	a characteristic appearance on serial ophthalmoscopic examinations (e.g., discrete patches of retinal whitening with distinct borders, spreading in a centrifugal manner, following blood vessels, progressing over several months, frequently associated with retinal vasculitis, hemorrhage, and necrosis). Resolution of active disease leaves retinal scarring and atrophy with retinal pigment epithelial mottling.
mycobacteriosis	microscopy of a specimen from stool or normally sterile body fluids or tissue from a site other than lungs, skin, or cervical or hilar lymph nodes, showing acid-fast bacilli of a species not identified by culture.
Kaposi's sarcoma	a characteristic gross appearance of an erythematous or violaceous plaque-like lesion on skin or mucous membrane. (**Note**: Presumptive diagnosis of Kaposi's sarcoma should not be made by clinicians who have seen few cases of it.)
lymphoid interstitial pneumonia	bilateral reticulonodular interstitial pulmonary infiltrates present on chest X ray for $\geq$2 months with no pathogen identified and no response to antibiotic treatment.
Pneumocystis carinii pneumonia	a. a history of dyspnea on exertion or nonproductive cough of recent onset (within the past 3 months); **AND** b. chest X-ray evidence of diffuse bilateral interstitial infiltrates or gallium scan evidence of diffuse bilateral pulmonary disease; **AND** c. arterial blood gas analysis showing an arterial pO_2 of $<$70 mm Hg or a low respiratory diffusing capacity ($<$80% of predicted values) or an increase in the alveolar-arterial oxygen tension gradient; **AND** d. no evidence of a bacterial pneumonia.

toxoplasmosis of the brain	a. recent onset of a focal neurologic abnormality consistent with intracranial disease or a reduced level of consciousness; **AND** b. brain imaging evidence of a lesion having a mass effect (on computed tomography or nuclear magnetic resonance) or the radiographic appearance of which is enhanced by injection of contrast medium; **AND** c. serum antibody to toxoplasmosis or successful response to therapy for toxoplasmosis.

APPENDIX IV

Equivalent Terms and International Classification of Disease (ICD) Codes for AIDS-Indicative Lymphomas

The following terms and codes describe lymphomas indicative of AIDS in patients with antibody evidence for HIV infection (Section II.A.8 of the AIDS case definition). Many of these terms are obsolete or equivalent to one another.

ICD-9-CM (1978)

Codes	Terms
200.0	**Reticulosarcoma** lymphoma (malignant): histiocytic (diffuse) reticulum cell sarcoma: pleomorphic cell type or not otherwise specified
200.2	**Burkitt's tumor or lymphoma** malignant lymphoma, Burkitt's type

ICD-O (Oncologic Histologic Types 1976)

Codes	Terms
9600/3	**Malignant lymphoma, undifferentiated cell type** non-Burkitt's or not otherwise specified
9601/3	**Malignant lymphoma, stem cell type** stem cell lymphoma
9612/3	**Malignant lymphoma, immunoblastic type** immunoblastic sarcoma, immunoblastic lymphoma, or immunoblastic lymphosarcoma
9632/3	**Malignant lymphoma, centroblastic type** diffuse or not otherwise specified, or germinoblastic sarcoma: diffuse or not otherwise specified
9633/3	**Malignant lymphoma, follicular center cell, non-cleaved** diffuse or not otherwise specified
9640/3	**Reticulosarcoma, not otherwise specified** malignant lymphoma, histiocytic: diffuse or not otherwise specified reticulum cell sarcoma, not otherwise specified malignant lymphoma, reticulum cell type
9641/3	**Reticulosarcoma, pleomorphic cell type** malignant lymphoma, histiocytic, pleomorphic cell type reticulum cell sarcoma, pleomorphic cell type
9750/3	**Burkitt's lymphoma or Burkitt's tumor** malignant lymphoma, undifferentiated, Burkitt's type malignant lymphoma, lymphoblastic, Burkitt's type

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MORBIDITY AND MORTALITY WEEKLY REPORT

228 Classification System for Human Immunodeficiency Virus (HIV) Infection in Children Under 13 Years of Age

Current Trends

Classification System for Human Immunodeficiency Virus (HIV) Infection in Children Under 13 Years of Age

INTRODUCTION

With the identification of the causative agent of the acquired immunodeficiency syndrome (AIDS), a broad spectrum of clinical manifestations has been attributed to infection with the human immunodeficiency virus (HIV). With the exception of the CDC surveillance definition for AIDS (*1,2*), no standard definitions for other manifestations of HIV infection have been developed for children. Classification systems published to date have been developed primarily to categorize clinical presentations in adult patients and may not be entirely applicable to infants and children (*3-5*).

Physicians from institutions caring for relatively large numbers of HIV-infected children report that only about half of their patients with symptomatic illness related to the infection fulfill the criteria of the CDC surveillance definition for AIDS (*6,7*).

To develop a classification system for HIV infection in children, CDC convened a panel of consultants* consisting of clinicians experienced in the diagnosis and management of children with HIV infection; public health physicians; representatives from the American Academy of Pediatrics, the Council of State and Territorial Epidemiologists, the Association for Maternal Child Health and Crippled Children's Programs, the National Institute on Drug Abuse/Alcohol, Drug Abuse and Mental Health Administration, the National Institute of Allergy and Infectious Diseases/National Institutes of Health, and the Division of Maternal and Child Health/Health Resources and Services Administration; and CDC.

GOALS AND OBJECTIVES OF THE CLASSIFICATION SYSTEM

The system was designed primarily for public health purposes, including epidemiologic studies, disease surveillance, prevention programs, and health-care planning and policy. The panel attempted to devise a simple scheme that could be subdivided as needed for different purposes.

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*P Brunell, MD, R Daum, MD, American Academy of Pediatrics; J Chin, MD, State Epidemiologist, California Dept of Health Svcs; L Cooper, MD, St Luke's-Roosevelt Hospital Center, New York City; J Oleske, MD, MPH, L Epstein, MD, Univ of Medicine and Dentistry of New Jersey; N Luban, MD, Children's Hospital National Medical Center, Washington, DC; S Mailloux, MD, Assoc of Maternal Child Health and Crippled Children's Programs; S Pawha, MD, North Shore Univ Hospital, Cornell University Medical Center, Manhassett, NY; G Scott, MD, Univ of Miami School of Medicine; R Stiehm, MD, Univ of California, Los Angeles; P Thomas, MD, New York City Dept of Health; D Ward, MD, Univ of California, San Francisco; D Williams, MD, Los Angeles County Hospital; J Witte, MD, MPH, Florida Dept of Health and Rehabilitative Svcs.

HIV Infection – Continued

DEFINITION OF HIV INFECTION IN CHILDREN (Table 1)

Ideally, HIV infection in children is identified by the presence of the virus in blood or tissues, confirmed by culture or other laboratory detection methods. However, current tests—including culture—for detecting the virus or its antigens are not standardized and are not readily available. Detection of specific antibody to the virus is a sensitive and specific indicator of HIV infection in adults, since the majority of adults with antibody have had culture evidence of infection (*8-10*). Similar studies involving children have not been reported. Also, the presence of passively transferred maternal antibody in infants limits the interpretation of a positive antibody test result in this age group. Most of the consultants believed that passively transferred maternal HIV antibody could sometimes persist for up to 15 months. For this reason, two definitions for infection in children are needed: one for infants and children up to 15 months of age who have been exposed to their infected mothers perinatally, and another for older children with perinatal infection and for infants and children of all ages acquiring the virus through other means.

Infants and children under 15 months of age with perinatal infection—Infection in infants and children up to 15 months of age who were exposed to infected mothers in the perinatal period may be defined by one or more of the following: 1) the identification of the virus in blood or tissues, 2) the presence of HIV antibody as indicated by a repeatedly reactive screening test (e.g., enzyme immunoassay) plus a positive confirmatory test (e.g., Western blot, immunofluorescence assay) in an infant or child who has abnormal immunologic test results indicating both humoral and cellular immunodeficiency (increased immunoglobulin levels, depressed T4 [T-helper] absolute cell count, absolute lymphopenia, decreased T4/T8 ratio) and who meets the requirements of one or more of the subclasses listed under class P-2 (described below), or 3) the confirmation that a child's symptoms meet the previously published CDC case definition for pediatric AIDS (*1,2*).

The infection status of other perinatally exposed seropositive infants and children up to 15 months of age who lack one of the above immunologic or clinical criteria is indeterminate. These infants should be followed up for HIV-related illness, and they should be tested at regu-

TABLE 1. Summary of the definition of HIV infection in children

Infants and children under 15 months of age with perinatal infection

1) Virus in blood or tissues
   or
2) HIV antibody
   and
   evidence of both cellular and humoral immune deficiency
   and
   one or more categories in Class P-2
   or
3) Symptoms meeting CDC case definition for AIDS

Older children with perinatal infection and children with HIV infection acquired through other modes of transmission

1) Virus in blood or tissues
   or
2) HIV antibody
   or
3) Symptoms meeting CDC case definition for AIDS

HIV Infection – Continued

lar intervals for persistence of antibody to HIV. Infants and children who become seronegative, are virus-culture negative (if blood or tissue samples are cultured), and continue to have no clinical or laboratory-confirmed abnormalities associated with HIV infection are unlikely to be infected.

Older children with perinatal infection and children with HIV infection acquired through other modes of transmission—HIV infection in these children is defined by one or more of the following: 1) the identification of virus in blood or tissues, 2) the presence of HIV antibody (positive screening test plus confirmatory test) regardless of whether immunologic abnormalities or signs or symptoms are present, or 3) the confirmation that the child's symptoms meet the previously published CDC case definition for pediatric AIDS (*1,2*).

These definitions apply to children under 13 years of age. Persons 13 years of age and older should be classified according to the adult classification system (*3*).

CLASSIFICATION SYSTEM (Table 2)

Children fulfilling the definition of HIV infection discussed above may be classified into one of two mutually exclusive classes based on the presence or absence of clinical signs and symptoms (Table 2). Class Pediatric-1 (P-1) is further subcategorized on the basis of the presence or absence of immunologic abnormalities, whereas Class P-2 is subdivided by specific disease patterns. Once a child has signs and symptoms and is therefore classified in P-2, he or she should not be reassigned to class P-1 if signs and symptoms resolve.

Perinatally exposed infants and children whose infection status is indeterminate are classified into class P-0.

Class P-0. Indeterminate infection. Includes perinatally exposed infants and children up to 15 months of age who cannot be classified as definitely infected according to the above definition but who have antibody to HIV, indicating exposure to a mother who is infected.

Class P-1. Asymptomatic infection. Includes patients who meet one of the above defini-

TABLE 2. Summary of the classification of HIV infection in children under 13 years of age

Class P-0. Indeterminate infection

Class P-1. Asymptomatic infection

- Subclass A. Normal immune function
- Subclass B. Abnormal immune function
- Subclass C. Immune function not tested

Class P-2. Symptomatic infection

- Subclass A. Nonspecific findings
- Subclass B. Progressive neurologic disease
- Subclass C. Lymphoid interstitial pneumonitis
- Subclass D. Secondary infectious diseases
  - Category D-1. Specified secondary infectious diseases listed in the CDC surveillance definition for AIDS
  - Category D-2. Recurrent serious bacterial infections
  - Category D-3. Other specified secondary infectious diseases
- Subclass E. Secondary cancers
  - Category E-1. Specified secondary cancers listed in the CDC surveillance definition for AIDS
  - Category E-2. Other cancers possibly secondary to HIV infection
- Subclass F. Other diseases possibly due to HIV infection

HIV Infection – Continued

tions for HIV infection but who have had no previous signs or symptoms that would have led to classification in Class P-2.

These children may be subclassified on the basis of immunologic testing. This testing should include quantitative immunoglobulins, complete blood count with differential, and T-lymphocyte subset quantitation. Results of functional testing of lymphocytes (mitogens, such as pokeweed) may also be abnormal in HIV-infected children, but it is less specific in comparison with immunoglobulin levels and lymphocyte subset analysis, and it may be impractical.

Subclass A - Normal immune function. Includes children with no immune abnormalities associated with HIV infection.

Subclass B - Abnormal immune function. Includes children with one or more of the commonly observed immune abnormalities associated with HIV infection, such as hypergammaglobulinemia, T-helper (T4) lymphopenia, decreased T-helper/T-suppressor (T4/T8) ratio, and absolute lymphopenia. Other causes of these abnormalities must be excluded.

Subclass C - Not tested. Includes children for whom no or incomplete (see above) immunologic testing has been done.

Class P-2. Symptomatic infection. Includes patients meeting the above definitions for HIV infection and having signs and symptoms of infection. Other causes of these signs and symptoms should be excluded. Subclasses are defined based on the type of signs and symptoms that are present. Patients may be classified in more than one subclass.

Subclass A - Nonspecific findings. Includes children with two or more unexplained nonspecific findings persisting for more than 2 months, including fever, failure-to-thrive or weight loss of more than 10% of baseline, hepatomegaly, splenomegaly, generalized lymphadenopathy (lymph nodes measuring at least 0.5 cm present in two or more sites, with bilateral lymph nodes counting as one site), parotitis, and diarrhea (three or more loose stools per day) that is either persistent or recurrent (defined as two or more episodes of diarrhea accompanied by dehydration within a 2-month period).

Subclass B - Progressive neurologic disease. Includes children with one or more of the following progressive findings: 1) loss of developmental milestones or intellectual ability, 2) impaired brain growth (acquired microcephaly and/or brain atrophy demonstrated on computerized tomographic scan or magnetic resonance imaging scan), or 3) progressive symmetrical motor deficits manifested by two or more of these findings: paresis, abnormal tone, pathologic reflexes, ataxia, or gait disturbance.

Subclass C - Lymphoid interstitial pneumonitis. Includes children with a histologically confirmed pneumonitis characterized by diffuse interstitial and peribronchiolar infiltration of lymphocytes and plasma cells and without identifiable pathogens, or, in the absence of a histologic diagnosis, a chronic pneumonitis—characterized by bilateral reticulonodular interstitial infiltrates with or without hilar lymphadenopathy—present on chest X-ray for a period of at least 2 months and unresponsive to appropriate antimicrobial therapy. Other causes of interstitial infiltrates should be excluded, such as tuberculosis, *Pneumocystis carinii* pneumonia, cytomegalovirus infection, or other viral or parasitic infections.

Subclass D - Secondary infectious diseases. Includes children with a diagnosis of an infectious disease that occurs as a result of immune deficiency caused by infection with HIV.

Category D-1. Includes patients with secondary infectious disease due to one of the specified infectious diseases listed in the CDC surveillance definition for AIDS: *Pneumocystis carinii* pneumonia; chronic cryptosporidiosis; disseminated toxoplasmosis with onset after 1 month of age; extra-intestinal strongyloidiasis; chronic isosporiasis; candidiasis (esophageal, bronchial, or pulmonary); extrapulmonary cryptococco-

HIV Infection – Continued

sis; disseminated histoplasmosis; noncutaneous, extrapulmonary, or disseminated mycobacterial infection (any species other than leprae); cytomegalovirus infection with onset after 1 month of age; chronic mucocutaneous or disseminated herpes simplex virus infection with onset after 1 month of age; extrapulmonary or disseminated coccidioidomycosis; nocardiosis; and progressive multifocal leukoencephalopathy.

Category D-2. Includes patients with unexplained, recurrent, serious bacterial infections (two or more within a 2-year period) including sepsis, meningitis, pneumonia, abscess of an internal organ, and bone/joint infections.

Category D-3. Includes patients with other infectious diseases, including oral candidiasis persisting for 2 months or more, two or more episodes of herpes stomatitis within a year, or multidermatomal or disseminated herpes zoster infection.

Subclass E - Secondary cancers. Includes children with any cancer described below in categories E-1 and E-2.

Category E-1. Includes patients with the diagnosis of one or more kinds of cancer known to be associated with HIV infection as listed in the surveillance definition of AIDS and indicative of a defect in cell-mediated immunity: Kaposi's sarcoma, B-cell non-Hodgkin's lymphoma, or primary lymphoma of the brain.

Category E-2. Includes patients with the diagnosis of other malignancies possibly associated with HIV infection.

Subclass F - Other diseases. Includes children with other conditions possibly due to HIV infection not listed in the above subclasses, such as hepatitis, cardiopathy, nephropathy, hematologic disorders (anemia, thrombocytopenia), and dermatologic diseases.

Reported by: AIDS Program, Center for Infectious Diseases, CDC.

Editorial Note: This classification system is based on present knowledge and understanding of pediatric HIV infection and may need to be revised as new information becomes available. New diagnostic tests, particularly antigen detection tests and HIV-specific IgM tests, may lead to a better definition of HIV infection in infants and children. Information from several natural history studies currently under way may necessitate changes in the subclasses based on clinical signs and symptoms.

A definitive diagnosis of HIV infection in perinatally exposed infants and children under 15 months of age can be difficult. The infection status of these HIV-seropositive infants and children who are asymptomatic without immune abnormalities cannot be determined unless virus culture or other antigen-detection tests are positive. Negative virus cultures do not necessarily mean the child is not infected, since the sensitivity of the culture may be low. Decreasing antibody titers have been helpful in diagnosing other perinatal infections, such as toxoplasmosis and cytomegalovirus. However, the pattern of HIV-antibody production in infants is not well defined. At present, close follow-up of these children (Class P-0) for signs and symptoms indicative of HIV infection and/or persistence of HIV antibody is recommended.

The parents of children with HIV infection should be evaluated for HIV infection, particularly the mother. The child is often the first person in such families to become symptomatic. When HIV infection in a child is suspected, a careful history should be taken to elicit possible risk factors for the parents and the child. Appropriate laboratory tests, including HIV serology, should be offered. If the mother is seropositive, other children should be evaluated regarding their risk of perinatally acquired infection. Intrafamilial transmission, other than perinatal or sexual, is extremely unlikely. Identification of other infected family members allows for appropriate medical care and prevention of transmission to sexual partners and future children (*11,12*).

HIV Infection – Continued

The nonspecific term AIDS-related complex has been widely used to describe symptomatic HIV-infected children who do not meet the CDC case definition for AIDS. This classification system categorizes these children more specifically under Class P-2.

The development and publication of this classification system does not imply any immediate change in the definition of pediatric AIDS used by CDC for reporting purposes (*1,2*). Changes in this definition require approval by state and local health departments. However, changes in the definition for reporting cases have been proposed by CDC and are awaiting state and local approval.

Written comments are encouraged. They should be mailed to the AIDS Program, Center for Infectious Diseases, Centers for Disease Control, Atlanta, GA 30333.

References

1. CDC. Update: acquired immunodeficiency syndrome (AIDS)—United States. MMWR 1984;32:688-91.
2. CDC. Revision of the case definition of acquired immunodeficiency syndrome for national reporting—United States. MMWR 1985;34:373-5.
3. CDC. Classification system for human T-lymphotropic virus type III/lymphadenopathy-associated virus infections. MMWR 1986;35:334-9.
4. Redfield RR, Wright DC, Tramont EC. The Walter Reed staging classification for HTLV-III/LAV infection. N Engl J Med 1986;314:131-2.

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MORBIDITY AND MORTALITY WEEKLY REPORT

Current Trends

Education and Foster Care of Children Infected with Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus

The information and recommendations contained in this document were developed and compiled by CDC in consultation with individuals appointed by their organizations to represent the Conference of State and Territorial Epidemiologists, the Association of State and Territorial Health Officers, the National Association of County Health Officers, the Division of Maternal and Child Health (Health Resources and Services Administration), the National Association for Elementary School Principals, the National Association of State School Nurse Consultants, the National Congress of Parents and Teachers, and the Children's Aid Society. The consultants also included the mother of a child with acquired immunodeficiency syndrome (AIDS), a legal advisor to a state education department, and several pediatricians who are experts in the field of pediatric AIDS. This document is made available to assist state and local health and education departments in developing guidelines for their particular situations and locations.

These recommendations apply to all children known to be infected with human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV). This includes children with AIDS as defined for reporting purposes (Table 1); children who are diagnosed by their physicians as having an illness due to infection with HTLV-III/LAV but who do not meet the case definition; and children who are asymptomatic but have virologic or serologic evidence of infection with HTLV-III/LAV. These recommendations do not apply to siblings of infected children unless they are also infected.

BACKGROUND

The Scope of the Problem. As of August 20, 1985, 183 of the 12,599 reported cases of AIDS in the United States were among children under 18 years of age. This number is expected to double in the next year. Children with AIDS have been reported from 23 states, the District of Columbia, and Puerto Rico, with 75% residing in New York, California, Florida, and New Jersey.

The 183 AIDS patients reported to CDC represent only the most severe form of HTLV-III/LAV infection, i.e., those children who develop opportunistic infections or malignancies (Table 1). As in adults with HTLV-III/LAV infection, many infected children may have milder illness or may be asymptomatic.

Legal Issues. Among the legal issues to be considered in forming guidelines for the education and foster care of HTLV-III/LAV-infected children are the civil rights aspects of public

HTLV-III/LAV – Continued

TABLE 1. Provisional case definition for acquired immunodeficiency syndrome (AIDS) surveillance of children

For the limited purposes of epidemiologic surveillance, CDC defines a case of pediatric acquired immunodeficiency syndrome (AIDS) as a child who has had:

1. A reliably diagnosed disease at least moderately indicative of underlying cellular immunodeficiency, and
2. No known cause of underlying cellular immunodeficiency or any other reduced resistance reported to be associated with that disease.

The diseases accepted as sufficiently indicative of underlying cellular immunodeficiency are the same as those used in defining AIDS in adults. In the absence of these opportunistic diseases, a histologically confirmed diagnosis of chronic lymphoid interstitial pneumonitis will be considered indicative of AIDS unless test(s) for HTLV-III/LAV are negative. Congenital infections, e.g., toxoplasmosis or herpes simplex virus infection in the first month after birth or cytomegalovirus infection in the first 6 months after birth must be exluded.

Specific conditions that must be excluded in a child are:

1. Primary immunodeficiency diseases—severe combined immunodeficiency, DiGeorge syndrome, Wiskott-Aldrich syndrome, ataxia-telangiectasia, graft versus host disease, neutropenia, neutrophil function abnormality, agammaglobulinemia, or hypogammaglobulinemia with raised IgM.
2. Secondary immunodeficiency associated with immunosuppressive therapy, lymphoreticular malignancy, or starvation.

school attendance, the protections for handicapped children under 20 U.S.C. 1401 et seq. and 29 U.S.C. 794, the confidentiality of a student's school record under state laws and under 20 U.S.C. 1232g, and employee right-to-know statutes for public employees in some states.

Confidentiality issues. The diagnosis of AIDS or associated illnesses evokes much fear from others in contact with the patient and may evoke suspicion of life styles that may not be acceptable to some persons. Parents of HTLV-III/LAV-infected children should be aware of the potential for social isolation should the child's condition become known to others in the care or educational setting. School, day-care, and social service personnel and others involved in educating and caring for these children should be sensitive to the need for confidentiality and the right to privacy in these cases.

ASSESSMENT OF RISKS

Risk Factors for Acquiring HTLV-III/LAV Infection and Transmission. In adults and adolescents, HLTV-III/LAV is transmitted primarily through sexual contact (homosexual or heterosexual) and through parenteral exposure to infected blood or blood products. HTLV-III/LAV has been isolated from blood, semen, saliva, and tears but transmission has not been documented from saliva and tears. Adults at increased risk for acquiring HTLV-III/LAV include homosexual/bisexual men, intravenous drug abusers, persons transfused with contaminated blood or blood products, and sexual contacts of persons with HTLV-III/LAV infection or in groups at increased risk for infection.

The majority of infected children acquire the virus from their infected mothers in the perinatal period (*1-4*). In utero or intrapartum transmission are likely, and one child reported from Australia apparently acquired the virus postnatally, possibly from ingestion of breast milk (*5*). Children may also become infected through transfusion of blood or blood products that contain the virus. Seventy percent of the pediatric cases reported to CDC occurred among children whose parent had AIDS or was a member of a group at increased risk of acquiring HTLV-III/LAV infection; 20% of the cases occurred among children who had received blood or blood products; and for 10%, investigations are incomplete.

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HTLV-III/LAV – Continued

Risk of Transmission in the School, Day-Care or Foster-Care Setting. None of the identified cases of HTLV-III/LAV infection in the United States are known to have been transmitted in the school, day-care, or foster-care setting or through other casual person-to-person contact. Other than the sexual partners of HTLV-III/LAV-infected patients and infants born to infected mothers, none of the family members of the over 12,000 AIDS patients reported to CDC have been reported to have AIDS. Six studies of family members of patients with HTLV-III/LAV infection have failed to demonstrate HTLV-III/LAV transmission to adults who were not sexual contacts of the infected patients or to older children who were not likely at risk from perinatal transmission (*6-11*).

Based on current evidence, casual person-to-person contact as would occur among schoolchildren appears to pose no risk. However, studies of the risk of transmission through contact between younger children and neurologically handicapped children who lack control of their body secretions are very limited. Based on experience with other communicable diseases, a theoretical potential for transmission would be greatest among these children. It should be emphasized that any theoretical transmission would most likely involve exposure of open skin lesions or mucous membranes to blood and possibly other body fluids of an infected person.

Risks to the Child with HTLV-III/LAV Infection. HTLV-III/LAV infection may result in immunodeficiency. Such children may have a greater risk of encountering infectious agents in a school or day-care setting than at home. Foster homes with multiple children may also increase the risk. In addition, younger children and neurologically handicapped children who may display behaviors such as mouthing of toys would be expected to be at greater risk for acquiring infections. Immunodepressed children are also at greater risk of suffering severe complications from such infections as chickenpox, cytomegalovirus, tuberculosis, herpes simplex, and measles. Assessment of the risk to the immunodepressed child is best made by the child's physician who is aware of the child's immune status. The risk of acquiring some infections, such as chickenpox, may be reduced by prompt use of specific immune globulin following a known exposure.

RECOMMENDATIONS

1. Decisions regarding the type of educational and care setting for HTLV-III/LAV-infected children should be based on the behavior, neurologic development, and physical condition of the child and the expected type of interaction with others in that setting. These decisions are best made using the team approach including the child's physician, public health personnel, the child's parent or guardian, and personnel associated with the proposed care or educational setting. In each case, risks and benefits to both the infected child and to others in the setting should be weighed.
2. For most infected school-aged children, the benefits of an unrestricted setting would outweigh the risks of their acquiring potentially harmful infections in the setting and the apparent nonexistent risk of transmission of HTLV-III/LAV. These children should be allowed to attend school and after-school day-care and to be placed in a foster home in an unrestricted setting.
3. For the infected preschool-aged child and for some neurologically handicapped children who lack control of their body secretions or who display behavior, such as biting, and those children who have uncoverable, oozing lesions, a more restricted environment is advisable until more is known about transmission in these settings. Children infected with HTLV-III/LAV should be cared for and educated in settings that minimize exposure of other children to blood or body fluids.

HTLV-III/LAV – Continued

4. Care involving exposure to the infected child's body fluids and excrement, such as feeding and diaper changing, should be performed by persons who are aware of the child's HTLV-III/LAV infection and the modes of possible transmission. In any setting involving an HTLV-III/LAV-infected person, good handwashing after exposure to blood and body fluids and before caring for another child should be observed, and gloves should be worn if open lesions are present on the caretaker's hands. Any open lesions on the infected person should also be covered.
5. Because other infections in addition to HTLV-III/LAV can be present in blood or body fluids, all schools and day-care facilities, regardless of whether children with HTLV-III/LAV infection are attending, should adopt routine procedures for handling blood or body fluids. Soiled surfaces should be promptly cleaned with disinfectants, such as household bleach (diluted 1 part bleach to 10 parts water). Disposable towels or tissues should be used whenever possible, and mops should be rinsed in the disinfectant. Those who are cleaning should avoid exposure of open skin lesions or mucous membranes to the blood or body fluids.
6. The hygienic practices of children with HTLV-III/LAV infection may improve as the child matures. Alternatively, the hygienic practices may deteriorate if the child's condition worsens. Evaluation to assess the need for a restricted environment should be performed regularly.
7. Physicians caring for children born to mothers with AIDS or at increased risk of acquiring HTLV-III/LAV infection should consider testing the children for evidence of HTLV-III/LAV infection for medical reasons. For example, vaccination of infected children with live virus vaccines, such as the measles-mumps-rubella vaccine (MMR), may be hazardous. These children also need to be followed closely for problems with growth and development and given prompt and aggressive therapy for infections and exposure to potentially lethal infections, such as varicella. In the event that an antiviral agent or other therapy for HTLV-III/LAV infection becomes available, these children should be considered for such therapy. Knowledge that a child is infected will allow parents and other caretakers to take precautions when exposed to the blood and body fluids of the child.
8. Adoption and foster-care agencies should consider adding HTLV-III/LAV screening to their routine medical evaluations of children at increased risk of infection before placement in the foster or adoptive home, since these parents must make decisions regarding the medical care of the child and must consider the possible social and psychological effects on their families.
9. Mandatory screening as a condition for school entry is not warranted based on available data.
10. Persons involved in the care and education of HTLV-III/LAV-infected children should respect the child's right to privacy, including maintaining confidential records. The number of personnel who are aware of the child's condition should be kept at a minimum needed to assure proper care of the child and to detect situations where the potential for transmission may increase (e.g., bleeding injury).
11. All educational and public health departments, regardless of whether HTLV-III/LAV-infected children are involved, are strongly encouraged to inform parents, children, and educators regarding HTLV-III/LAV and its transmission. Such education would greatly assist efforts to provide the best care and education for infected children while minimizing the risk of transmission to others.

HTLV-III/LAV – Continued

References

1. Scott GB, Buck BE, Leterman JG, Bloom FL, Parks WP. Acquired immunodeficiency syndrome in infants. N Engl J Med 1984;310:76-81.
2. Thomas PA, Jaffe HW, Spira TJ, Reiss R, Guerrero IC, Auerbach D. Unexplained immunodeficiency in children. A surveillance report. JAMA 1984;252:639-44.
3. Rubinstein A, Sicklick M, Gupta A, et al. Acquired immunodeficiency with reversed T4:T8 ratios in infants born to promiscuous and drug-addicted mothers. JAMA 1983;249:2350-6.
4. Oleske J, Minnefor A, Cooper R Jr, et al. Immune deficiency syndrome in children. JAMA 1983; 249:2345-9.
5. Ziegler JB, Cooper DA, Johnson RO, Gold J. Postnatal transmission of AIDS-associated retrovirus from mother to infant. Lancet 1985;i:896-8.
6. CDC. Unpublished data.
7. Kaplan JE, Oleske JM, Getchell JP, et al. Evidence against transmission of HTLV-III/LAV in families of children with AIDS. Pediatric Infectious Disease (in press).
8. Lewin EB, Zack R, Ayodele A. Communicability of AIDS in a foster care setting. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.
9. Thomas PA, Lubin K, Enlow RW, Getchell J. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city mothers in New York. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.
10. Fischl MA, Dickinson G, Scott G, Klimas N, Fletcher M, Parks W. Evaluation of household contacts of adult patients with the acquired immunodeficiency syndrome. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.
11. Friedland GH, Saltzman BR, Rogers MF, et al. Lack of household transmission of HTLV-III infection. EIS Conference, Atlanta, Georgia, April 1985.

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Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome

The information and recommendations in this document are intended to assist health-care providers and state and local health departments in developing procedures to prevent perinatal transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV), the virus that causes acquired immunodeficiency syndrome (AIDS).

This document contains recommendations for providing counselling and, when indicated, testing for antibody to HTLV-III/LAV for women who are at increased risk of acquiring the virus and who are either pregnant or may become pregnant. It is important that these women know they are at risk, as well as know and understand their HTLV-III/LAV-antibody status, so they can make informed decisions to help prevent perinatally acquired HTLV-III/LAV.

Through counselling, uninfected women can learn how to avoid becoming infected, and infected women can choose to delay pregnancy until more is known about perinatal transmission of the virus. If already pregnant, infected women can be provided information for managing the pregnancy and caring for the child.

Currently available data indicate that most pediatric HTLV-III/LAV infections and AIDS are acquired perinatally from infected women, but additional studies are needed to better quantify the risk of transmission from an infected pregnant woman to the fetus or newborn.

The recommendations below pertain to women. However, men who are HTLV-III/LAV-antibody positive should also be counselled regarding the risks of sexual and perinatal transmission, so they can refer for counselling and testing their sex partners who may be pregnant or considering pregnancy.

BACKGROUND

Pediatric AIDS Cases due to Perinatal Transmission. As of December 1, 1985, 217 (1%) of the 15,172 AIDS cases reported to CDC occurred among children under 13 years of age. Sixty percent of these children are known to have died. These 217 cases represent only the more severe manifestations of HTLV-III/LAV infection. Less severe manifestations, often described as AIDS-related complex (ARC), are not reported to CDC, so the number of children with clinically significant illness attributable to HTLV-III/LAV infection is greater than the reported cases of pediatric AIDS. In addition, a number of infected children are probably asymptomatic.

HTLV-III/LAV – Continued

Of the 217 reported pediatric AIDS patients, 165 (76%) have as their only known risk factor a mother belonging to a group with increased prevalence of HTLV-III/LAV infection. An additional 18% of the pediatric cases are attributable to transfusions of blood or blood products, while risk factor information is missing or incomplete on the remaining 6%. Of the 217 children with AIDS, 48% had mothers who were intravenous (IV) drug abusers; 17% had mothers who were born in Haiti, and 10% had mothers who were sex partners of either IV drug abusers or bisexual men.

Of the patients with perinatally acquired AIDS, 45% resided in New York City, while Florida and New Jersey accounted for an additional 32%.

Mechanisms of Perinatal Transmission. It is believed that HTLV-III/LAV is transmitted from infected women to their fetuses or offspring during pregnancy, during labor and delivery, or perhaps shortly after birth. Transmission of the virus during pregnancy or labor and delivery is demonstrated by two reported AIDS cases occurring in children who had no contact with their infected mothers after birth. One was delivered by Cesarean section (*1,2*).

Transmission of the virus after birth has been implicated in one case of HTLV-III/LAV infection in a child born to a mother reported to have acquired the infection from a postpartum blood transfusion. Since she breastfed the child for 6 weeks, the authors suggested breastfeeding as the possible mode of transmission (*3*). Recently, HTLV-III/LAV has been isolated from the breast milk of infected women (*4*).

Risk of Perinatal Transmission from Infected Mothers. The rate of perinatal transmission of HTLV-III/LAV from infected pregnant women is unknown; however, available data suggest a high rate. In one study of 20 infants born to infected mothers who had already delivered one infant with AIDS, 13 (65%) had serologic and/or clinical evidence of infection with HTLV-III/LAV several months after birth (*5,6*). Since these women were selected on the basis of having previously transmitted HTLV-III/LAV perinatally, this study may overestimate the average risk of transmission for all infected pregnant women.

Perinatal transmission from an infected mother to her newborn is not inevitable. Of three children born to women who became infected with HTLV-III/LAV by artificial insemination from an infected donor, all were in good health and negative for antibody to the virus more than 1 year after birth (*7*). Another child, born to a woman who was already pregnant at the time of AIDS diagnosis and was demonstrated to be viremic, was seronegative, culture negative, and healthy at birth and at 4 months of age (*8*). In a retrospective study evaluating nine children under 5 years of age whose mothers were later diagnosed with AIDS, two (22%) had antibody to HTLV-III/LAV (*9*). The infection status of these women during pregnancy was unknown.

In these studies, the rate of transmission ranged from 0% (0/3) to 65% (13/20). Additional studies are needed to better define the rate of transmission and variables associated with it.

Risk of Illness among Infected Pregnant Women. Pregnancy is associated with suppression of cell-mediated immunity and increased susceptibility to some infections (*10*). The T-helper to T-suppressor ratio is decreased during normal pregnancy, being lowest in the third trimester, and returns to normal approximately 3 months postpartum (*10*). It is not known whether pregnancy increases an infected woman's risk of developing AIDS or ARC, but one study suggests it does (*6*). Fifteen infected women who were well at time of delivery were followed an average of 30 months after the births of their children. Five (33%) subsequently developed AIDS, seven (47%) developed AIDS-related conditions, and only three (20%) remained asymptomatic. These results may not apply to all infected pregnant women, but they do suggest an increased likelihood of developing disease when an HTLV-III/LAV infection occurs in association with pregnancy.

HTLV-III/LAV – Continued

Prevalence of HTLV-III/LAV Infection. Counselling and testing for antibody to HTLV-III/LAV when indicated, to reduce perinatal transmission of AIDS will be most beneficial in populations of women with increased prevalence of the virus (Table 1). These include: women who have used drugs intravenously for nonmedical purposes; women who were born in countries where heterosexual transmission is thought to play a major role (*11,12*); women who have engaged in prostitution; and women who are or have been sex partners of men who abuse IV drugs, are bisexual, have hemophilia, were born in countries where heterosexual transmission is thought to play a major role (*11,12*), or have evidence of HTLV-III/LAV infection.

The prevalence of antibody to HTLV-III/LAV in U.S. populations of men and women ranges from less than 0.01% in female blood donors to as high as 74% in men with hemophilia (*13-15*). Among heterosexual IV drug abusers, the prevalence of HTLV-III/LAV infection ranges from 2% to 59% in various geographic areas (*16,17*). Seroprevalence among the heterosexual partners of persons at increased risk for AIDS varies from 10% in female partners of asymptomatic, seropositive hemophilia patients to 71% in the female partners of men with AIDS or ARC (*18-20*). Among prostitutes, the HTLV-III/LAV antibody prevalence varies from 5% to 40%, depending on geographic area, with most of the women with positive tests relating histories of IV drug abuse (*21*). Among female blood donors in Atlanta, Georgia, who

TABLE 1. Prevalence of HTLV-III/LAV antibody in heterosexual populations — United States

Populations	Location	No. tested	Prevalence (%)
Intravenous drug abusers (*16,17*)	New York City	274	59
	NJ* < 5 miles from NYC†	204	56
	NJ 5-10 miles from NYC	124	43
	NJ > 100 miles from NYC	55	2
	San Francisco	53	9
Persons with hemophilia (*13,14*)			
Factor VIII concentrate recipients		234	74
Factor IX concentrate recipients		36	39
Cryoprecipitate only recipients		15	40
Female prostitutes (*21*)	Seattle, Washington	92	5
	Miami, Florida	25	40
Female sex partners of men with AIDS or ARC (two separate studies) (*19,20*)		7	71
		42	47
Female sex partners of men with asymptomatic HTLV-III/LAV infection (*18*)		21	10
Haitians (*12*)	New York City	97	4
	Miami, Florida	129	8
Female blood donors (*15*)	Atlanta, Georgia	28,354	0.01

*New Jersey

†New York City

HTLV-III/LAV – Continued

denied belonging to high-risk groups, 0.01% had repeatedly reactive enzyme-linked immunosorbent assays (ELISAs) followed by reactive Western blot tests (*15*).

Commercially available tests to detect antibody to HTLV-III/LAV are ELISAs using antigens derived from whole disrupted HTLV-III/LAV. When the ELISA is reactive on initial testing, it is standard procedure to repeat the test on the same specimen. Repeatedly reactive tests are highly sensitive and specific for antibody to HTLV-III/LAV. However, when the ELISA is used to screen populations in which the prevalence of infection is very low (such as blood donors or women not in high-risk groups), the proportion of repeatedly reactive results that are falsely positive will be higher. For that reason, an additional test, such as a Western blot, is recommended following repeatedly reactive ELISA results, especially in low-prevalence populations. In populations with high prevalence of infection (e.g. homosexual men or IV drug abusers), most repeatedly reactive ELISAs are reactive by Western blot or another test. For example, among 109 IV drug abusers whose sera were repeatedly reactive by ELISA, over 85% were reactive by Western blot (*22*). In contrast, in a low-prevalence population of 69 female blood donors whose sera were repeatedly reactive by ELISA, only 5% were reactive by Western blot (*15*).

Due to the seriousness of the implications of HTLV-III/LAV-antibody reactivity, it is recommended that repeatedly reactive ELISAs be followed by an additional test, such as the Western blot. Women with sera repeatedly reactive by ELISA and reactive by Western blot should have a thorough medical evaluation. HTLV-III/LAV has been isolated from a single specimen in 67%-95% of persons with specific antibody (*23,24*). Because infection has been demonstrated in asymptomatic persons, the presence of specific antibody should be considered presumptive evidence of current infection and infectiousness.

RECOMMENDATIONS

Women Who Should be Offered Counselling and Testing. *Counselling services and testing for antibody to HTLV-III/LAV should be offered to pregnant women and women who may become pregnant in the following groups:* (1) those who have evidence of HTLV-III/LAV infection, (2) those who have used drugs intravenously for nonmedical purposes, (3) those who were born in countries where heterosexual transmission is thought to play a major role (*11,12*), (4) those who have engaged in prostitution, (5) those who are or have been sex partners of: IV drug abusers, bisexual men, men with hemophilia, men who were born in countries where heterosexual transmission is thought to play a major role (*11,12*), or men who otherwise have evidence of HTLV-III/LAV infection. If data become available to show that HTLV-III/LAV-antibody prevalence is increased in other groups or settings, counselling and testing programs should be extended to include them. Routine counselling and testing of women who are not included in the above-mentioned groups is not recommended due to low prevalence of infection and concern about interpretation of test results in a low-prevalence population. However if a woman requests it, the service should be provided in accordance with these recommendations.

Settings for Offering Counselling and Testing. Counselling and testing for antibody to HTLV-III/LAV to prevent perinatal transmission is recommended in the setting of any medical service in which women at increased risk are commonly encountered. These include services for treating IV drug abuse (i.e., detoxification and methadone maintenance), comprehensive hemophilia treatment centers, sexually transmitted disease clinics, and clinics that serve female prostitutes. In addition, services related to reproduction, such as family planning and infertility services, gynecologic, premarital, or preconceptual examinations, and prenatal and

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HTLV-III/LAV – Continued

obstetric services should also consider offering counselling and testing if high-risk women are seen at these facilities. Testing for antibody to HTLV-III/LAV should be performed with the woman's consent after counselling is provided regarding risk factors for infection, the interpretation of test results, the risks of transmission, and the possible increased likelihood of disease among women infected with HTLV-III/LAV in association with pregnancy. The counselling and testing must be conducted in an environment in which confidentiality can be assured. In settings where confidential counselling and testing cannot be assured, information should be provided and referrals made to appropriate facilities.

Frequency of Testing. Detectable antibodies to HTLV-III/LAV may not develop until 2-4 months after exposure. This, and whether the woman is continuously exposed, should be taken into account when considering the need for, and frequency of, repeat testing. High-risk women should be offered counselling and testing before they become pregnant. During pregnancy, counselling and testing should be offered as soon as the woman is known to be pregnant. If the initial test is negative, repeat testing may be indicated near delivery to aid in the clinical management of the pregnant woman and newborn. If this final test is negative and the mother's risk of exposure no longer exists, she may safely consider breastfeeding the child, and management of the child need not include the same concerns that would be appropriate if the woman had had a positive test or if she were at high risk and had not been tested at all.

Counselling Women with Positive Results. Women with virologic or serologic evidence of HTLV-III-LAV infection should be counselled regarding their own risk of AIDS and the risk of perinatal and sexual transmission of HTLV-III/LAV. Infected women should be counselled to refer their sex partners for counselling and testing. If the partners of these women are not infected, both members of the couple should be counselled on how they may modify their sexual practices to reduce the risk of HTLV-III/LAV transmission to the uninfected partner. In addition, the couple should be told not to donate blood, organs, or sperm and should be discouraged from using IV drugs and advised against sharing needles and syringes. When seeking medical or dental care for intercurrent illness, they should inform those responsible for their care of their positive antibody status so appropriate evaluation can be undertaken. Recommendations for providing information and advice to individuals infected with HTLV-III/LAV have been published (*25*).

Infected women should be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus. Pregnant infected women may require additional medical and social support services due to an enhanced risk of opportunistic infections and psychosocial difficulties during and after pregnancy. Obstetric-care providers should be alert to signs and symptoms of HTLV-III/LAV and related opportunistic infections in these pregnant women and to the need for specialized medical care.

HTLV-III/LAV-infected women should be advised against breastfeeding to avoid postnatal transmission to a child who may not yet be infected. The child should receive follow-up pediatric evaluations to determine whether he/she has HTLV-III/LAV infection, and to diagnose and treat promptly any diseases that may be secondary to HTLV-III/LAV infection. Recommendations for educating and providing foster care for infected children have been published (*26*).

Counselling Women with Negative Test Results. A negative ELISA for HTLV-III/LAV antibody in women who have no clinical or laboratory evidence of HTLV-III/LAV infection is evidence that they have probably not been infected. However, uninfected women who have sex

HTLV-III/LAV – Continued

partners with evidence of HTLV-III/LAV infection or with an increased risk of becoming infected should be informed that sexual intercourse increases their risk of infection. These women should be informed of the risks associated with pregnancy if they become infected and advised to consider delaying pregnancy until more is known about perinatal transmission of the virus or until they are no longer considered to be at risk for acquiring the virus. In addition to preventing pregnancy, the consistent and proper use of condoms can offer some protection against HTLV-III/LAV infection.

High-risk women, even if seronegative, should be told not to donate blood or organs. To decrease their risk of becoming infected, IV drug abusers should be encouraged to seek treatment for their drug abuse. Persons counselling IV drug abusers should know that IV drug abuse is often strongly ingrained and compulsive. Despite educational efforts and encouragement for treatment, some addicts will continue to abuse drugs or relapse after treatment. If drug abuse continues, they should be advised not to share needles or syringes and to use only sterile equipment.

HTLV-III/LAV – Continued

Additional Considerations. These recommendations will be revised as additional information becomes available. It is recognized that provision of the recommended professional counselling, HTLV-III/LAV-antibody testing and associated specialized medical services will take time to implement and may stress available resources, particularly in public facilities, which are most greatly affected. Health-care providers, social-service personnel, and others involved in educating and caring for HTLV-III/LAV-infected persons should be aware of the potential for social isolation and should be sensitive to the need for confidentiality. They should be familiar with federal and state laws, regulations, and policies that protect the confidentiality of clinical data and test results. Each institution should assure that specific mechanisms are in place to protect the confidentiality of all records and to prevent the misuse of information. Anonymous testing would not be appropriate if it prevents adequate counselling and medical follow-up evaluation.

Hospital precautions for managing infected women and infants should be patterned after those for caring for patients with HTLV-III/LAV infection (*27,28*). Additional recommendations will follow.

DEVELOPMENT OF THESE RECOMMENDATIONS

The information and recommendations contained in this document were developed and compiled by CDC and the U.S. Public Health Service in consultation with individuals representing the Conference of State and Territorial Epidemiologists, the Association of State and Territorial Health Officials, the American Public Health Association, the United States Conference of Local Health Officers, the American Medical Association, the American College of Obstetricians and Gynecologists, the American Academy of Pediatrics, the Planned Parenthood Federation of America, the American Venereal Disease Association, the Division of Maternal and Child Health of the Health Resources and Services Administration, the National Institute on Drug Abuse of the Alcohol, Drug Abuse, and Mental Health Administration, the National Hemophilia Foundation, the Haitian Medical Association, the American Bar Foundation, and the Kennedy Institute of Ethics at Georgetown University. The consultants also included representatives of the departments of health of the areas with the largest number of perinatally transmitted pediatric AIDS cases: New York City, Florida, and New Jersey. These recommendations may not reflect the views of all individual consultants or the organizations they represented.

References

1. Lapointe N, Michaud J, Pekovic D, Chausseau JP, Dupuy JM. Transplacental transmission of HTLV-III virus. [Letter] N Engl J Med 1985;312:1325-6.
2. Cowan MJ, Hellmann D, Chudwin D, Ware DW, Chang RS, Ammann AJ. Maternal transmission of acquired immune deficiency syndrome. Pediatrics 1984;73:382-6.
3. Ziegler JB, Cooper DA, Johnson RO, Gold J. Postnatal transmission of AIDS-associated retrovirus from mother to infant. Lancet 1985;i:896-7.
4. Thiry L, Sprecher-Goldberger S, Jonckheer T, et al. Isolation of AIDS virus from cell-free breast milk of three healthy virus carriers. [Letter] Lancet 1985;ii:891-2.
5. Scott GB, Fischl MA, Klimas N, et al. Mothers of infants with the acquired immunodeficiency syndrome: outcome of subsequent pregnancies. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
6. Scott GB, Fischl MA, Klimas N, et al. Mothers of infants with the acquired immunodeficiency syndrome: evidence for both symptomatic and asymptomatic carriers. JAMA 1985;253:363-6.
7. Stewart GJ, Tyler JPP, Cunningham AL, et al. Transmission of human T-lymphotropic virus type III (HTLV-III) virus by artificial insemination by donor. Lancet 1985;ii:581-4.
8. CDC. Unpublished data.
9. Thomas PA, Lubin K, Enlow RW, Getchell J. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city

HTLV-III/LAV – Continued

mothers in New York. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.

10. Weinberg ED. Pregnancy-associated depression of cell-mediated immunity. Rev Inf Dis 1984;6:814-31.
11. WHO. Acquired immune deficiency syndrome (AIDS): Report on the situation in Europe as of 31 December 1984. Weekly Epidemiological Record 1985;60:85-92.
12. Castro KG, Fischl MA, Landesman SH, et al. Risk factors for AIDS among Haitians in the United States. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
13. Jason J, McDougal JS, Holman RC, et al. Human T-lymphotropic retrovirus type III lymphadenopathy-associated virus antibody: association with hemophiliacs' immune status and blood component usage. JAMA 1985; 253:3409-15.
14. Gjerset GF, McGrady G, Counts RB, et al. Lymphadenopathy-associated virus antibodies and T cells in hemophiliacs treated with cryoprecipitate or concentrate. Blood 1985;66:718-20.
15. CDC. Unpublished data.
16. Spira TJ, Des Jarlais DC, Bokos D, et al. HTLV-III/LAV antibodies in intravenous drug abusers: comparison of low and high risk areas for AIDS. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
17. Weiss SH, Ginzburg HM, Goedert JJ, et al. Risk for HTLV-III exposure and AIDS among parenteral drug abusers in New Jersey. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
18. Kreiss JK, Kitchen LW, Prince HE, Kasyer CK, Essex M. Antibody to human T-lymphotropic virus type III in wives of hemophiliacs: evidence for heterosexual transmission. Ann Intern Med 1985; 102:623-6.
19. Redfield RR, Markham PD, Salahuddin SZ, et al. Frequent transmission of HTLV-III among spouses of patients with AIDS-related complex and AIDS. JAMA 1985;253:1571-3.
20. Harris CA, Cabradilla CD, Robert-Guroff M, et al. HTLV-III/LAV infection and AIDS in heterosexual partners of AIDS patients. Minneapolis, Minnesota: Twenty-fifth interscience conference on antimicrobial agents and chemotherapy, September 29-October 2, 1985.
21. CDC. Heterosexual transmission of human T-lymphotropic virus type III lymphadenopathy-associated virus. MMWR 1985;34:561-3.
22. CDC. Unpublished data.
23. Feorino PM, Jaffe HW, Palmer E, et al. Transfusion-associated acquired immunodeficiency syndrome: evidence for persistent infection in blood donors. N Engl J Med 1985;312:1293-6.
24. Jaffe HW, Feorino PM, Darrow WW, et al. Persistent infection with human T-lymphotropic virus type III-lymphadenopathy-associated virus in apparently healthy homosexual men. Ann Intern Med 1985;102:627-30.
25. CDC. Provisional Public Health Service inter-agency recommendations for screening donated blood and plasma for antibody to the virus causing acquired immunodeficiency syndrome. MMWR 1985;34:1-5.
26. CDC. Education and foster care of children infected with human T-lymphotropic virus type III/lymphadenopathy-associated virus. MMWR 1985;34:517-21.
27. CDC. Acquired immune deficiency syndrome (AIDS): precautions for clinical and laboratory staffs. MMWR 1982;31:577-80.
28. CDC. Recommendations for preventing transmission of infection with human T-lymphotropic virus type III/lymphadenopathy-associated virus in the workplace. MMWR 1985;34:681-6, 691-5.

APPENDIX III

RESOURCE LISTING

APPENDIX III

RESOURCE LISTING

I. FEDERAL AGENCIES

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE (PHS)
Office of Public Affairs
200 Independence Ave., S.W.
Room 725-H
Washington, D.C. 20201

* Surgeon General's Report on Acquired Immune Deficiency Syndrome

Additional AIDS information materials available from the PHS:

* "Facts About AIDS"
* "AIDS and Children - Information for Parents of School Age Children"
* "AIDS and Children - Information for Teachers and School Officials"
* "AIDS Sex and You"
* "Facts About AIDS and Drug Abuse"
* "AIDS: Fears and Facts"

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL
Office of Public Inquiries
Bldg. 1, Rm. B-63
1600 Clifton Rd.
Atlanta, GA. 30333
404-329-3534

* Acquired Immunodeficiency Syndrome. AIDS. Recommendations and Guidelines. November 1982-November 1986.
* AIDS: Information/Education Plan to Prevent and Control AIDS in the U.S., 1987.
* "AIDS Information for Young People"
* "AIDS and Shooting Drugs"

NATIONAL COMMISSION TO PREVENT INFANT MORTALITY
Switzer Building
Room 2006
330 C Street, S.W.
Washington, D.C. 20201
202-472-1364

* "Perinatal AIDS. Care for our Children. Care for our Future." October 1987.

II. NATIONAL ORGANIZATIONS

AMERICAN ACADEMY OF PEDIATRICS
DEPARTMENT OF MATERNAL, CHILD, AND ADOLESCENT HEALTH
141 Northwest Point Blvd.
Elk Grove, IL 60009
800-433-9016

AMERICAN RED CROSS
AIDS Education Office
1730 D Street, N.W.
Washington, D.C. 20006
202-737-8300

The following AIDS information materials are available from the national Red Cross office or local chapter offices:

* "AIDS: Spread Facts, Not Fear"
* "Beyond Fear"
* AIDS Prevention Program for Youth:
  "A Letter From Brian" (film/video)
  A student/participant text/workbook
  A leaders/teachers guide
  Parent support brochure

AMERICAN FEDERATION OF TEACHERS,
555 New Jersey Ave., N.W.
WASHINGTON, D.C., 1987.
202-879-4507

* "AIDS Education in the Classroom. Focus on Education Series"

AMERICAN COUNCIL OF LIFE INSURANCE
Health Insurance Association of America
Department 190
1001 PENNSYLVANIA AVE., N.W.
WASHINGTON, D.C. 20004
Att: Eve Katz
202-624-2424

* "Teens and AIDS: Playing it Safe"

CENTER FOR POPULATION OPTIONS
1012 14th St., N.W.
Suite 1200
Washington, D.C. 20005
202-347-5700

* "AIDS and Adolescents: The Time for Prevention is Now" November 1987.

INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES
2101 Constitution Ave. N.W.
Washington, D.C. 20418
202-334-2169

* Confronting AIDS: Directions for Public Health, Health Care and Research

NATIONAL EDUCATION ASSOCIATION
1201 16th Street, N.W.
Washington, D.C. 20036
NEA Health Information Network

* "The Facts About AIDS," September 1987.

NATIONAL SCHOOL BOARDS ASSOCIATION
1680 Duke St.
Alexandria, VA 22314
202-838-6722

* "AIDS and the Public Schools. Leadership Report Vol. I"

III. UNIVERSITY-BASED PROJECTS

AIDS EDUCATION PROJECT
State University of New York
Stonybrook, New York
516-444-3246
Att: Betty Coppola

* "Medical, Psychological and Social Implications of AIDS: A Curriculum for Young Adults"

AIDS HEALTH PROJECT
University of California
Box 0884
San Francisco, CA. 94143
415-476-6430

* "Working with AIDS: A Resource Guide for Mental Health Professionals"

INTERGOVERNMENTAL HEALTH POLICY PROJECT
George Washington University
2011 I Street, N.W.
Suite 200
Washington, D.C. 20006
202--872-1390

* "AIDS: A Public Health Challenge to the States"

SEX INFORMATION AND EDUCATION COUNCIL OF THE U.S. - SEICUS
New York University
32 Washington Place
New York, New York 10003
212-673-3850

* "How to Talk to Your Children about AIDS"

IV. STATE AND LOCAL DEPARTMENTS OF HEALTH AND EDUCATION

The following list is illustrative of state and local education and health department initiatives on AIDS

AIDS INSTITUTE
New York State Health Department
Albany, New York
518-442-3300

* 100 QUESTIONS AND ANSWERS ABOUT AIDS

AIDS ACTIVITY UNIT
Ohio Department of Health
246 N. High St.
P.O. Box 118
Columbus, Ohio 43266
614-466-0265
Att: Rachelle Randolph

* AIDS VIRUS INFORMATION PACKAGE

LEARNER SUPPORT SYSTEMS
Minnesota Department of Education
550 Cedar St., Room 996
St. Paul, Minnesota 55101
612-296-4080
Att: Martha Arnold

* PRESENTING AIDS: A RESOURCE GUIDE FOR INSERVICE EDUCATION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME AND EDUCATIONAL IMPLICATIONS

COMPREHENSIVE HEALTH EDUCATION OFFICE
Dade County Unified School District
1450 N.E. 2nd Ave.
Miami, Fla. 33132
305-376-1000

* AIDS: ACQUIRED IMMUNE DEFICIENCY SYNDROME

OFFICE OF HEALTH AND PHYSICAL EDUCATION
New York City Board of Education
347 Baltic St., Room 202
Brooklyn, New York 11201
718-935-2000
Att: Gerri Abelson

* FAMILY LIVING INCLUDING SEX EDUCATION-SUPPLEMENTARY MATERIAL RELATED TO AIDS

PUBLICATIONS OFFICE
LOS ANGELES UNIFIED SCHOOL DISTRICT
450 N. Grand Ave.
Los Angeles, CA. 90012
213-625-6432
Att: Norm Haugaues

* NEW PATHWAYS TO HEALTH LESSONS FOR TEACHING ABOUT THE S.T.D.'S

V. NATIONAL AIDS HOTLINE

PUBLIC HEALTH SERVICE NATIONAL AIDS HOTLINE:

1-800-342-2437

ADDITIONAL VIEWS OF THE HON. BARBARA BOXER, HON. GEORGE MILLER, HON. WILLIAM LEHMAN, HON. PATRICIA SCHROEDER, HON. BERYL ANTHONY, JR., HON. SANDER M. LEVIN, HON. BRUCE A. MORRISON, HON. GERRY SIKORSKI, HON. ALAN WHEAT, HON. LANE EVANS, HON. RICHARD J. DURBIN, AND HON. THOMAS C. SAWYER

We are deeply disappointed and shocked by the Reagan Administration's lack of response to the public health crisis created by the AIDS epidemic. The Surgeon General has often been a lonely voice in the Administration, in his clear, unequivocal calls for concern, compassion and action. The Administration's appalling silence for six years after AIDS was first diagnosed in 1981, and its refusal or inability to spearhead and implement a nationwide, comprehensive AIDS education plan, in our view, are tragically inexcusable, contributing to the spiraling death toll.

Clearly, AIDS threatens the health and lives of all Americans. More than 47,000 AIDS cases, including some 700 cases among infants and young children and nearly 200 adolescent cases, have been reported since the epidemic began, and their numbers are increasing.

The Public Health Service estimates that by the end of 1991, there will be more than 270,000 diagnosed AIDS cases in the United States, and more than 179,000 people will have died from the disease. The numbers of babies and young children with AIDS is expected to increase several-fold in the next five years, to more than 3,000 cases by the end of 1991.

The threat to young children and adolescents has largely been buried in the tide of the epidemic so far. However, we now see hundreds of infants and young children with AIDS. The

increasing majority of these children have been infected perinatally by mothers who used intravenous drugs and shared contaminated needles or who became infected through sexual contact with an infected partner. The problems already experienced by adolescents, such as their rates of sexually transmitted diseases, as well as the experimenting nature of their development, place them at serious risk too.

The Select Committee has followed the insidious increase in AIDS cases among young children and adolescents, documenting the potential for disastrous consequences for a generation should we not act responsibly now. This report underscores the urgency of that need.

The economic toll of AIDS is equally staggering: The Public Health Service estimates that in 1991 alone it will cost anywhere from $8 billion to $16 billion to care for the thousands upon thousands of AIDS patients in the U.S. Because this does not include care for those with AIDS-related illnesses or individuals who test positive for AIDS but have not yet developed full-blown AIDS, this is a very conservative estimate.

Historically, what have Americans done in response to a public health crisis?

We can give a good example: In the 1940's, hospital corridors across out Nation were packed with polio victims -- mostly children -- in wheelchairs and iron-lungs. In that day, we had a president we could count on to set goals and lead efforts to guide us through the crisis. Americans responded to the threat of polio not by throwing their hands up in despair, but by

pulling together, by uniting forces to develop a vaccine, find a cure and protect themselves.

That record lies in stark contrast with the overall dismal record of the Reagan Administration on AIDS.

It took President Reagan six years after AIDS was first diagnosed in 1981 even to publicly acknowledge it. He finally said that AIDS is America's number one public health priority, but there is little substance backing up this rhetoric.

Until a vaccine or cure is found and becomes available, education in the only tool we have to prevent the spread of this deadly disease. Sadly, though, instead of a campaign of loud and clear life-saving messages, educational efforts have been an ideological battleground.

In fact, some in this Administration seem to be exploiting the AIDS issue to launch a crusade against educational efforts proposed by the Centers for Disease Control (CDC), the federal agency charged with monitoring and combatting AIDS on the public health education front. It has become very clear that some in this Administration have been guided more by far right wing ideology than by the need to save lives. Meanwhile, more and more Americans are becoming infected, not informed.

We have no problem with saying that abstinence is the most effective way to stop the sexual transmission of AIDS. We should get the abstinence message out, for in this era of AIDS, there truly is no such thing as "safe sex" unless both partners have always been monogamous.

However, that's far from enough.

We have the responsibility to educate all Americans about how to lower their risks of becoming infected through sexual contact. We must face up to the problems of drug use and do a much better job of educating everyone about the now even more deadly threat of I.V. drug abuse and the sharing of contaminated needles.

And, most important and lacking to date, we must back up our commitments with the federal leadership and resources to implement and sustain clear action.

Since 1981, Congress has requested millions of dollars each year for AIDS research, treatment and education in budget negotiations. President Reagan's proposals have consistently lagged far behind -- usually less than half the congressional figures.

After six years of appropriating millions of dollars for AIDS education, what do we have to show for it? Not much.

It was only a few months ago that the Administration finally unveiled a public relations campaign -- video tapes and brochures -- so vaguely worded that its effectiveness is questionable. And, instead of taking the lead on its very own effort, this Administration prefers to pass the buck and leave the task of distributing these materials to states, private groups and networks.

Earlier this year, the Administration was planning a massive, nationwide mailing of an AIDS education booklet to

each household. We thought that was an excellent idea, already done in England with very positive results.

In July, Congress earmarked $20 million to pay for the mailing. The CDC drafted proposed copy for the booklet, but after it reached Reagan's Domestic Policy Council, the idea was dropped, reportedly to placate arch-conservatives opposed to distributing medically explicit material. Now Administration officials are saying there are no plans for a direct, mass mailing.

The real tragedy is that while Adminstration officials are busy slugging it out over ideology, more and more Americans are literally dying of ignorance.

Early this year, 38 members of Congress -- both Republicans and Democrats -- requested copies of U.S. Surgeon General Koop's report on AIDS for their constituents. Twenty million of these have been printed. Many of these members had to wait three to four months to get the reports. Some members who requested the report more than five months ago are still waiting to receive all of them.

This defies reality. Every year the federal government manages to send millions of IRS forms to its citizens on time. Why can't it get out the Surgeon General's report?

Even the long-awaited Presidential Commission appointed this year to study AIDS has been crippled by infighting and resignations, and its report is not due until next summer.

The President has appeared on television in recent weeks,

appealing for confirmation of his Supreme Court nominees and trying to calm fears about our roller-coaster stock market. Why can't he find the time and courage to go on the air and tell Americans how to save their lives?

Even the few effective and cost-saving state and local efforts continue to struggle to meet the challenge of AIDS, with little help and sometimes outright resistance from the federal government.

We urge the President to use the last months of his term to provide the leadership and vision our Nation desperately needs to fight AIDS effectively.

We must dramatically expand our health care facilities and services to meet the needs of both advanced AIDS patients and those with AIDS-related illnesses.

We must step up data gathering efforts to improve policy making and services for those with or at risk of AIDS. To date, with the exception of minimal epidemiological data, information about AIDS and young children and adolescents is scarce.

The National Academy of Sciences' Institute of Medicine has recommended that by 1990 the U.S. should be spending $2 billion a year -- $1 billion for research, and $1 billion for education. We must do our best to meet these goals.

We should immediately implement a comprehensive, national public education campaign to tell all Americans what steps they must take to save their lives.

We must, in addition, support voluntary AIDS testing, and we must provide counseling for those who test positive for the AIDS antibodies. At the same time, we must guarantee that test results are kept confidential and that AIDS patients and their families are protected by law from discrimination.

That's the American way.

We must send a clear message that abuse and ostracism of AIDS victims and their families -- like the Rays in Arcadia, Florida or Ryan White in Kokomo, Indiana -- will not be tolerated in this Nation.

The bottom line is that AIDS is a public health crisis -- a national threat that cries out for national leadership.

Whether we want to face it or not, we <u>all</u> have a stake in the fight against AIDS. It targets children, adults, Republicans, Democrats, liberals, conservatives, whites, blacks, Hispanics, rich and poor.

If we all don't unite to stop its deadly march, we will have to pay a far higher price in lives and grief in the years to come.

Barbara Boxer
George Miller, Chairman
William Lehman
Patricia Schroeder
Beryl Anthony, Jr.
Sander M. Levin
Bruce a Morrison
Gerry Sikorski
Alan Wheat
Lane Evans
Richard J. Durbin
Thomas C. Sawyer

ADDITIONAL VIEWS OF THE HON. SANDER LEVIN

A GENERATION IN JEOPARDY: CHILDREN AND AIDS
December 1987

This report by the Select Committee on Children, Youth, and Families is an important contribution to our national fight against AIDS. As a nation, we are struggling to respond effectively to the AIDS crisis. We must prevent the spread of the disease through public education and individual counseling. We must guarantee access to humane treatment and social services for persons with AIDS. We must protect against panic and unwarranted discrimination that threaten to worsen this health crisis. It may be that concern for our children, more than any other factor, will stimulate the leadership and public education that are so necessary. My own experiences in the 17th Congressional District of Michigan underscore the need for this kind of informative effort.

Unlike urban centers on the East and West coasts, the Detroit Metropolitan area is just beginning to feel the devastating effects of AIDS. In terms of the spread of the epidemic, Detroit is where New York was approximately five years ago. The virus is spreading most rapidly among intravenous drug users. However, Detroit still has an opportunity to learn from the experiences of other cities. We do not have to watch AIDS spread to infect 50 to 80% of IV drug abusers and their partners. We do not have to see further increases in the rate of children born with AIDS. Michigan can and must respond with informed leadership to prevent further devastation.

This year, I mailed the Surgeon General's Report on AIDS to every household in the 17th District. This mailing was

followed by a series of town meetings and by a community leadership conference on AIDS. The response of the community was clear -- people are willing to learn more and respond constructively to the threat of AIDS, and concern for the health and safety of children is especially high. Grandmothers said they would share the Surgeon General's Report with their grandchildren. A nun shared the information with her Catholic high school class, which in turn organized a school-wide assembly on AIDS. Parents wanted to learn how to protect their children. A minister promised to preach a sermon on AIDS.

These people wanted information. They wanted to see more frequent and more thorough press coverage about AIDS. They wanted authoritative information about how the virus is and is not spread. They very much appreciated the opportunity to have their questions answered by informed, reliable experts. It is clear to me that any efforts to promote public education about AIDS will be appreciated and helpful. We should not hesitate in our efforts in this regard.

On the other hand, I also learned that while AIDS is an issue of real concern in Michigan, to most people it still seems remote. While there was a strong positive response on the part of a handful of my constituents to the Surgeon General's Report and the town meetings, initially, there was a larger, non-response overall. Attendance at the first autumn town meetings was much lower than I expected. By winter, however, stronger follow-up efforts and a special outreach to community leaders seemed to boost active interest and attendance in the town meetings.

This pattern was an indication to me of the remoteness of

the AIDS issue for many people in my district. Because the epidemic has not yet spread widely, because most people still do not know someone who has died of AIDS, and because any discussion of AIDS inevitably involves discussion of sex, drug abuse, and death, there is understandably a great deal of avoidance. People would prefer that the whole problem would just go away.

That is why leadership is important. I believe we can evoke on a broader scale the positive willingness I witnessed on a small scale if we provide the necessary leadership. If we ensure a continual stream of authoritative information about AIDS prevention and transmission, and if we pursue rational policies to contain the epidemic and protect against discrimination, I believe we will find the popular support and cooperation necessary to protect our children and win the fight against AIDS.

In this respect, I would conclude by commending the impressive leadership provided by Surgeon General C. Everett Koop. Dr. Koop has been forceful and straightforward in his public education campaign. His testimony before the Select Committee and his subsequent publications have stressed our responsibility to teach our children about AIDS.

> We must tell young people the truth about AIDS and about the way it's spread. We must talk sense to them, and their parents, and their teachers. This is no rose garden. But we've got to make the effort. We have to educate and inform them, even though we do so in the midst of all the other complex aspects of sexual relations in America. Their lives are at stake, and so is the physical and spiritual life of this country.

There is no option but strong, clear leadership from the

government to confront this crisis. We have already suffered the consequences of weak leadership from the President and divided responses from within his administration. This is intolerable in the battle against AIDS, which is a struggle between life and death and a struggle to protect our most vital resource -- our human resources, including the children of America.

Sander M. Levin

ADDITIONAL VIEWS OF HONORABLE TED WEISS

"AIDS AND CHILDREN: A GENERATION IN JEOPARDY"

DECEMBER 3, 1987

Forty-seven thousand people have been diagnosed with AIDS -- including nearly 700 children under 13 years of age -- and more than 26,000 are dead. But these numbers pale when compared with projections for the future. The National Academy of Sciences and the Public Health Service tell us that by the end of 1991 there will be 270,000 persons who will have become sick or will have died because of AIDS. In 1991 alone, 75,000 are expected to be newly diagnosed with AIDS. The additional tragedy is that of the 75,000 persons expected to develop AIDS in 1991, only one-half are among the 1 to 1.5 million infected today.

Prevention is the only vaccine we have against AIDS. It is possible to prevent this steady progression to infection and to death. Prevention strategies mounted by community organizations and state and local governments in certain localities are having a positive effect. But the federal Administration, whom history will surely judge to have missed the opportunity to prevent many of the AIDS deaths, is mired in right-wing conceptual morality, debating issues that have nothing to do with the way people live their lives in the real world, and nothing to do with the way AIDS will ever be arrested.

Testimony presented to this committee established that between 70 and 80 percent of America's youth under the age of

20 are sexually active. Clearly, urging abstention and issuing advice on moral behavior by themselves are painfully inadequate.

Young children and teenagers should be the beneficiaries of enlightened educational programs, materials and counseling to help them to grow up avoiding risk-taking behaviors; and women in high-risk groups should be a special target of prevention strategies, for most pediatric AIDS is acquired perinatally.

Health care and housing for persons with AIDS -- including especially the single parent who has AIDS or who has a child who has AIDS -- are sorely neglected problems that must be addressed so that their lives can be continued in the most comfortable, compassionate and medically efficient manner.

Dedicated scientists in the Public Health Service have from the earliest stages of this cruel epidemic worked tirelessly to solve the mysteries of the AIDS virus. In a few short years they have made substantial progress in spite of the absence of adequate support from the Reagan Administration. But despite the Administration's reluctance to request and spend funds adequate to maintain momentum in the search for treatment and a vaccine, the federal AIDS budget has increased annually, largely because of the forceful leadership the Congress has demonstrated year after year.

We in Congress have been compelled to pressure, push and urge a reluctant Administration to request, and then to spend, more money for research, health care, and other desperately needed resources. Although we cannot legislate a cure for AIDS, we can provide funds for the Public Health Service's

education, surveillance, research, and health care activities. Until an Administration is in place which accepts responsibility for leading the government toward a rational, effective and compassionate response to the AIDS crisis, Congress must continue to provide such leadership. This report is a significant continuation of that effort.

Ted Weiss

ADDITIONAL VIEWS OF HON. THOMAS J. BLILEY, JR.

I deeply regret that I am unable to sign either the majority report or the minority views to accompany A Generation in Jeopardy: Children and AIDS. I decline to do so not because I disagree with the entire substance presented (I am strongly inclined to agree with the views presented by the minority); rather I disagree vehemently with the procedure used in drafting this report.

Unfortunately, this report is perhaps the most vivid example to date of this Committee's failure to live up to the commitment that it would operate in a bipartisan manner. As a member of this Committee, neither I nor my staff was informed that this report was in the works until the meeting to adopt it was noticed -- less than three full days prior to the meeting itself.

I was informed by the minority staff that a draft of this report was made available to the minority staff in early November on the condition that it not be shown to the Members of the Committee. This is outrageous. Never in my service in the Congress have I witnessed such a blatant disregard for elected Members of that body and the committee process.

I must state for the record that instances like this make it difficult for me to support the continued existence of this Committee. Clearly, the members of the Select Committee on Children, Youth, and Families, the Members of the House, and the American people have been ill-served in this matter.

Thomas J. Bliley, Jr., M.C.

DISSENTING MINORITY VIEWS OF HON. DAN COATS, RANKING MINORITY MEMBER; HON. FRANK WOLF; HON. BARBARA VUCANOVICH; HON. JACK KEMP; HON. RON PACKARD; HON. BEAU BOULTER; HON. DENNY HASTERT; HON. CLYDE HOLLOWAY

The Majority report is an alarming document. It reveals frightening facts about little children left to die by drug abusing mothers. But it is careful not to point a finger at mothers who abuse drugs and infect their babies with the deadly virus, and then leave them in hospitals to die.

The Majority report is alarming in the sense that it documents the incredible costs of treatment of AIDS patients, but says very little about measures that ought to be put into place to prevent this disease from spreading.

The Majority report is alarming in that it sends a warning to the American people that our children are in jeopardy but then its only message to combat this threat is early sex education emphasizing condom use.

Finally, the Majority document is alarming because it is an attempt to identify policy options to halt the spread of AIDS without clearly laying out all we know about the virus.

How can our hearts not cry out for the victims? Even if the statistics do not in fact suggest an entire generation is at risk, the potential that an entire generation could be at risk should compel us to act. In reading the Majority report one gets the feeling that the Majority is uncertain whether it wants to believe a generation is in jeopardy or not. The Majority apparently is not comfortable with the implications of its own report. If AIDS can be compared to a plague, that risks death for tens of thousands and potentially millions, then decisive action that changes lifestyles

is critical.

Certainly, if a generation is at risk, the recommendation that condoms (with extraordinarily high rates of failure in the most common method of transmission - anal sex) and sex education courses (that are value-free and do not have a good track record of preventing other sexually transmitted diseases or teen pregnancies) are going to solve the problem is woefully inadequate. This report urges solutions that are so limited as to be irrelevant to babies who get AIDS from drug abusing mothers, or children who get AIDS from drug abusing or bisexual fathers who sexually abuse them, or teenage hemophiliacs who get AIDS from contaminated blood supplies. The preventive measures suggested do not logically flow from the definition of the AIDS problems in children.

The core of our dissent from the Majority report is based upon the following points:

1) Most children, especially infants, get AIDS from adults. If we are serious about protecting children from AIDS, the focus must be on stopping the spread of AIDS among adults as fast as possible. The Majority report never clearly states this basic truth.

2) The number one means of transmission of AIDS is through anal intercourse, most common among homosexuals. The Majority report not only does not clearly state this, it repeatedly downplays the pivotal role anal intercourse and homosexuality has played and continues to play in the AIDS crisis.

3) Infected homosexual IV drug-users, especially in inner

cities and so-called "shooting galleries," have spread it to heterosexuals. The numbers are still small, and since the CDC recently revised its definition of AIDS, it is not clear that the heterosexual spread of AIDS is growing. However, we face a potential epidemic among certain categories of heterosexuals (i.e. those abusing drugs and those married to bisexuals) and children infected by adults with AIDS.

4) This report indirectly hints at the truth that family, character, and responsibility are the keys to solving this problem, yet it pays only "lip service" at best to ideas that could produce real changes. The Majority report states no less than five times that 70% of teens are sexually active by age 20. Through repetition, they seem to want readers of this report to become conditioned to accept the current level of teenage sexual activity is an unchangeable fact of life.

5) Condom failure rates guarantee that there is no such thing as "safe sex." It may be "safer sex" but, for example, it needs to be clearly stated that the failure rates in anal intercourse are hardly what most people would call safe.

6) The Majority report criticizes the level of funding available. We would argue that probably the biggest spending void at this time is in the area of preventing the disease. Spending cannot keep up with demand unless aggressive prevention is undertaken. We need more caring for the potential victims.

The following Minority views document our concerns about the

AIDS crisis and the Majority report. The pain, agony and death of AIDS will not be stopped unless we honestly confront the key facts. Defining the problem correctly is a necessary first step to solving the AIDS crisis. The Majority introduction called for avoidance of ideology, yet in their failure to go beyond ideology, they are in danger of failing to help the generation that may be in jeopardy.

We need a reasonable, comprehensive national strategy against AIDS based on two principles - caring and responsibility. This must include the following elements: detection, prevention, education, treatment, and research. We need compassionate care for the individuals afflicted and responsibility toward potential victims.

These views are not a comprehensive national strategy as such but they hopefully point toward the direction we need to head. We are disappointed that the Committee report seems to only offer so little toward a comprehension of and a solution to the problem of AIDS and children.

I. INFANTS AND YOUNG CHILDREN

A. AIDS AMONG INFANTS AND YOUNG CHILDREN INCREASING DRAMATICALLY IN THREE RISK GROUPS

CURRENT CENTER FOR DISEASE CONTROL (CDC) STATISTICS SHOW THAT WHILE THE NUMBER OF CASES OF PEDIATRIC AIDS ARE INCREASING, THE INCREASE IS LARGELY WITHIN CERTAIN RISK GROUPS

As of November 23, 1987, 682 cases had been reported to the CDC. Of these 682 cases, 516 children contracted the disease from their mothers, 90 were infected through transfusion and 40 cases were due to treatment of a blood clotting disorder. What needs to be stated very clearly here is that 95% of all cases of pediatric AIDS fall into these three risk groups, with the other 5% being cases whose record is incomplete, still under investigation, or without identifiable risk. (AIDS Weekly Surveillance Report, CDC, November 23, 1987)

Unless Dramatic Action Is Taken the Rapid Increase in Childhood AIDS Will Probably Continue as Long as IV Drug Use Continues

Those areas that have a high incidence of IV drug use will continue to have the highest numbers of pediatric AIDS cases. The Committee report points out that most cases of AIDS are currently in San Francisco and New York City, with most cases of childhood AIDS in New York, New Jersey, and Florida. Assuming the virus spreads via homosexuals and/or IV drug users with AIDS to additional cities, the projection is that 80% of AIDS cases will occur outside San Francisco and New York City by 1991.

The projected increases in pediatric AIDS are derived from the estimated numbers of female IV drug users at child bearing age. Nationwide, the number of IV drug users has been estimated to be between 400,000 and up to 700,000, with probably more than one million including those who occasionally use IV drugs. (CRS, 1987)

Unfortunately, there is little accurate information on the extent to which the AIDS virus has infected childbearing women. More ominously, as a recent study in the Journal of the American Medical Association noted:

> There are no data on the seroprevalence of HIV among sexually active women in inner cities, where a large number of men who are intravenous drug abusers live in close sexual and social contact with a pool of women of reproductive age.

The growing number of pediatric AIDS cases in areas with high levels of IV drug use will be stopped only when public health authorities obtain this much-needed information. Routine testing of women of childbearing age in areas reporting high levels of HIV seropositivity is essential if we are going to contain this manifestation of the epidemic.

Congressman William Dannemeyer's amendment to H.R. 1326, the Public Health Service Infant Mortality Amendments Act of 1987, is a good first step in this direction. Adopted on November 9th by a voice vote of the House of Representatives, the Dannemeyer Amendment would require operators of community migrant health centers to offer an AIDS test to any female receiving medical services at a community health center. Dannemeyer estimates his amendment would apply to approximately four million women who visit these centers each year.

B. MINORITY CHILDREN DISPROPORTIONATELY AFFECTED BY AIDS INFECTION DUE TO HIGH RATES OF IV DRUG USE IN MINORITY GROUP

> Nearly 80% of all the children with AIDS are either black or Hispanic and more than 70% of all women with AIDS are members of a minority group. (Larry Thompson, Washington Post Health, August 11, 1987)

Much attention has been paid to the increasing geographic spread of the AIDS virus. What is too often overlooked in the spread of this disease is the relationship between IV drug use in a community and the

rate of infection.

> Since the majority of perinatally acquired AIDS cases are linked to IV drug abusers, the demographic characteristics of these children are similar to those of IV drug users with AIDS. Most (88%) of these children are black or of Hispanic ethnicity. The prevalence of AIDS in black and Hispanic children is 15 and 9 times that in white, non-Hispanic children. (C. Everett Koop, Surgeon General, Testimony before the Select Committee on Narcotics Abuse and Control, July 27, 1987)

The disproportionate number of minority children affected by the AIDS virus is a very serious problem. These children are too often faced with single parent families in IV drug abusing communities that place them at risk of school failure and poor health.

The problem of minority children and AIDS is very much a problem of IV drug use within those communities of the inner cities. Whereas the problem of AIDS in the white community has been predominantly related to homosexuality it is more closely related to IV drug use among minorities, with the possible exception of the Haitians.

These facts about the minority population are critical for understanding the spread of AIDS especially in light of information that shows that risk groups are likely to remain stable.

> There is some reason to suppose it will stay confined to these groups for the foreseeable future...the risk groups will be much the same in five years as at present. (The New York Times, February 4, 1987)

C. GROWING NUMBERS OF CHILDREN WITH AIDS TRAGICALLY ABANDONED AND ORPHANED BY THEIR FAMILIES

The tragedy of children with AIDS or "border babies" abandoned in hospitals must be a priority. These children are victimized by the mothers who bore them.

What are the experiences of these babies? Senator Howard Metzenbaum, in testimony before the Subcommittee on Select Education of the Committee on Education and Labor (October 22, 1987), quoted a recent Washington Post front-page article:

> Last July, a drug addict, 7 months pregnant, was admitted to Harlem Hospital Center in labor. Within hours she delivered a one and a half pound baby. The next day she checked out of the hospital, leaving behind a daughter she did not name.

Mr. Metzenbaum then stated:

> Today that 9-month-old baby whose weight hovers around six and one half pounds--lighter than many new-borns--is dying of AIDS in the hospital she never left. Doctors say she got the disease from her mother, who returned only once for a visit.
>
> The baby, who has spent her life encased in an oxygen tent, hooked up to a heart monitor, a nasal feeding tube and an intravenous antibiotic line, is a member of a fast-growing second generation of AIDS victims: infected babies, most of whom are born to drug-addict parents who are dying of the disease.

What do we know about these babies?

> -Young children with HIV infection typically have at least one drug-abusing parent. When there is such a parent in the family, there may be at least one other child also with HIV infection. The family obviously has serious problems.
>
> -Children with clinical AIDS typically have two to three stays in a hospital per year, with each hospital stay running approximately 10 to 15 days...
>
> -Hospitals have not yet analyzed data on the costs of care for these children, which are just now beginning to be available. Such analyses are underway. However, in general, hospitals report that the costs of health care for children with AIDS are higher than for care for adults with AIDS. Estimated adult AIDS patients' care costs range between $20,000 and $76,000 per year...
>
> (Robert H. Parrott, M.D., testimony before the Subcommittee on Select Education, Committee on Education and Labor, October 22, 1987.)

While research for a cure needs to be high on the list of funding priorities, it is clear to the Minority that money needs to be set aside specifically to treat and to prevent children from acquiring AIDS from their mothers.

The Department of Health and Human Services has undertaken a number of activities designed to prevent pediatric AIDS. None of these activities were mentioned in the Majority report. They include: research at NIH to study the natural history of AIDS, and rates of perinatal transmission and drug treatment for children with AIDS. Studies with AZT in children are ongoing:

> The early results are quite promising: in several children who had either learning problems or some evidence of neurological impairment because of AIDS, all showed improvement after receiving AZT...CDC awarded funds for several new pediatric projects including studies to assess the rates of infection in young children in three high-prevalence geographical areas. Studies are also being undertaken to assess rates of infection in adolescents and to define more clearly high-risk behavior in this age group. (Koop, Testimony before the Committee on Education and Labor, Oct. 22, 1987)

These studies will focus prevention efforts on children and youth, and the Minority believes these efforts are critical.

The Office of Human Development Services has earmarked $1.2 million for proposals to demonstrate innovative approaches to providing child welfare services for infants and young children with AIDS. Day care, respite care, foster family care and community-based alternatives to hospitalization will be activities considered for funding. Sick babies need help and the Minority wants to see those babies get it. We believe that the current and proposed funding under HHS and NIH to prevent and treat pediatric AIDS ought to be a priority.

We applaud the efforts made by localities with the greatest numbers of pediatric AIDS for responding. It appears that the most promising

alternatives for caring for AIDS babies comes from New York and California. In New York, Mayor Koch recently testified that:

> AIDS spending for treatment, testing, counseling, education, and other programs in fiscal 1988 will be $378 million, of which $100 million is city funds. (Mayor Edward Koch, testimony before the Select Committee on Narcotics Abuse and Control, July 27, 1987)

There is no doubt that children suffering from AIDS should not be subject to further abuses by either the hospital systems or the foster care systems. Innovative strategies need to be developed. There is no disagreement that more effective and cost-efficient options are needed. Indeed, it is the right thing to do.

It is also clear that the only way to reduce the potential explosion of AIDS among the children of IV drug users is to hold those mothers accountable for their behavior.

There is very little in this report about responsibility. We read of the horror stories of children being abandoned to die a painful death alone but nothing of consequences for those who killed them. For the most part, AIDS, as the Majority report notes, is a disease that can be prevented, a fact that the Majority report repeats numerous times. Therefore, it is a disease for which, in most cases, one should be held responsible for its knowing transmission.

In the Majority report it is stated that the cost of caring for abandoned infants with AIDS at the Harlem Hospital was $219,000 per year, with a cost range up to $2400 per day. These costs are so overwhelming that it would most likely result in reductions in spending for other needed programs, if society could or would support such expenditures on a large scale. If we really care about these kids, we must prevent maternal IV drug abuse and focus on accountability because adequate care is likely to be of limited availability - after the child is born AIDS infected is, after all, too late.

II. AIDS and ADOLESCENTS: A TIME BOMB?

A. THE HETEROSEXUAL BREAKOUT

> Discussing the sexual transmission of AIDS without mentioning homosexual behavior in general and anal sex in particular is like discussing syphilis without mentioning intercourse. (Michael A. Fumento, Commentary, November 1987)

The Majority report's discussion of adolescents is based upon the threat of a heterosexual breakout of AIDS. The dangers of homosexual activity and IV drug use are minimized. Anal intercourse is never mentioned. "Gay and lesbian youth," the Report says, "present special concerns," but only because "these teens, in struggling with their sexuality, frequently may have anonymous homosexual encounters distant from home while maintaining and engaging in heterosexual relationships in their neighborhoods."

But the reality is quite different. As of June, 1987, 40% of all AIDS cases among 13-19 year olds were homosexual or bisexual males, 7% were IV drug abusers, and another 7% were both homosexual and IV drug abusers.(1) Thomas Starcher, Director of AIDS Surveillance for the CDC, explains that though the CDC does not have the exact number of adolescents thought to have received the AIDS virus through heterosexual transmission, he believes that number to be "few, if any."(2)

Among adults, the overwhelming danger to homosexual males and IV drug abusers is well-documented. Sixty-six percent of all cases aged 13 and up are homosexual or bisexual males; 17% are IV drug abusers; and 8% are both homosexual and drug abusers; only 2% are American born individuals believed to have contracted the disease heterosexually.(3) The Center for Disease Control's chief

epidemiologist, Dr. Harold Jaffe, has stated:

> Those who are suggesting that we are going to see an explosive spread of AIDS in the heterosexual population have to explain why this isn't happening.(4)

The question of tertiary transmission is of greatest importance to the spread of AIDS among heterosexuals. If tertiary transmission remains rare then AIDS cannot spread far through heterosexual means. Because CDC does not maintain figures on tertiary transmission, one researcher sought information from individual cities:

> ...I contacted the four cities with the highest numbers of AIDS cases directly. In three of them the numbers of heterosexually transmitted cases were altogether so small - 18 of 3,661 cases in San Francisco, 30 out of 3,459 in Los Angeles, 12 out of 1,344 in Houston - as to leave little room for tertiary transmissions. New York City, with one-third of all reported AIDS cases, has the dubious distinction of being the nation's AIDS capital; its epidemic is also thought to be slightly more mature than that in San Francisco or Los Angeles; and its tracking and identification of cases are probably the best in the world. Of 11,217 AIDS victims, New York reports that "zero" have been second-generation heterosexual.(4)

In support of the contention that heterosexual transmission of AIDS is increasing, the Majority Report cites evidence from three sources showing a higher than average female/male ratio among HIV positive persons. The Majority argument and rebuttals to them follow:

1. Results of the first six months of HIV testing of civilian applicants to the military revealed that of those testing positive for HIV antibodies, the male to female ratio was 2.69:1.

   a. A report by the CDC to the Domestic Policy Council cites corrected rates among military applicants: 5.5:1.(5)

b. Military statistics showing males who have contracted AIDS from females have not held up well under scrutiny, as is demonstrated by the following account.(6)

> In Colorado, county health workers near the military bases of Colorado Springs were able to re-interview 20 active duty persons who had tested positive. Of that group, 14 ultimately admitted to homosexual contact, whereas only four had admitted it to Army interviewers: three others were in fact IV drug users, whereas the Army had found only one. The civilian researchers, who specialized in investigating sexually transmitted diseases, found that only one of the original 20 fell clearly into the heterosexual transmission category.
>
> A similar re-evaluation of the data in New York City also called into question the military statistics. The largest number of AIDS-positive recruits were in that area, and 25% of them, or 23, subsequently called the city Health Department's hot line for advice.
>
> At first, many claimed they had contracted AIDS from heterosexual contact with prostitutes, but later changed their story. Of the 20 who agreed to come into the Health Department office for counseling, 18 fell into the high-risk categories, with 10 admitting to intravenous drug use and an eight to homosexual activity. The one woman in the group said she had sex with an IV drug user. The one man who might have contracted it from heterosexual sex alone turned out, on retesting, not to be AIDS positive.

2. Dr.Hein also provided evidence suggesting increasing heterosexual transmission of the AIDS virus among adolescents by noting that among New York City adolescent AIDS cases, the male to female ratio is 2.8:1.

a. Roughly one third of the nation's IV drug abusers reside in New York City. Studies have found IV drug abusers in New York City have an infection rate of about 60%.(7) The one high risk group which is not overwhelmingly male is IV drug abusers: in this group the male/female ratio is about 1:1.(5)

b. Studies show that most other cities have HIV infection rates among IV drug abusers far lower than New York City's. Central

New Jersey has a 39% infection rate, Los Angeles has 2.8%; San Antonio 0-2%; Baltimore has 29%; Denver 5%; Tampa, Florida zero.(7) Only cities on the East Coast have infection rates higher than 5%.(5) Therefore, it would stand to reason that NYC would also have a higher percentage of AIDS cases who were drug abusers and their female partners, but such a percentage would indicate nothing about the rest of the country.

3. A recent study at an inner city STD clinic found that 6.3% of the men and 3% of the women were HIV-infected. Of those with positive test results, one third of the men and nearly 50% of the women were infected heterosexually.

a. This study was conducted in Baltimore where (as cited earlier) HIV infection among IV drug abusers is estimated at 29%.

b. The Baltimore study found a higher rate of infection among heterosexuals (not acknowledging other risk factors) than any other study. Other STD clinic studies have found rates of heterosexual infection (excluding other risk factors) of 0.5% in NYC, 0.2% in Denver, and 0% in Seattle.(5)

c. In other studies, risk behavior was ascertained by more reliable methods than that used in the Baltimore study. For example, the New York City study, ascertained risk behavior through in-person interviews. In the Baltimore study, however, risk behavior was ascertained through anonymous self-administered questionaires.(5)

B. WHY HASN'T AIDS SPREAD FASTER AMONG HETEROSEXUALS?

A recent study of 96 women who were the regular sexual partners of IV drug abusers and bisexual men with AIDS and with the AIDS virus showed that the women's risk of infection was significantly increased by anal intercourse, and the frequency of intercourse. Though only 23% of the women became infected with the AIDS virus, women who practiced rectal sex were nearly 2 1/2 times more likely to become HIV positive than those who did not. Also, infected women were nearly five times more likely to have had at least 100 sexual contacts with the HIV positive men.(9) From this study some experts have estimated the heterosexual transmission rates from men to women to be about 1 in 1,000 contacts. (4,10)

Many experts are also coming to believe that it is much more difficult for the AIDS virus to be transmitted from a woman to a man than from a man to a woman. Of 885 patients identified by the CDC as having received the virus through heterosexual contact, only about 20% were men. Of these, 40% were reported from New York City which subsequently screened these cases and found only 3 men who appeared to have contracted AIDS from women.(6)

One apparent explanation for the low numbers of female-to-male transmission of the AIDS virus consists in the absence of AIDS most common facilitator; receptive anal intercourse. A second possible explanation is that the virus exists in vaginal secretions in far lower levels than in semen and blood, both of which contain high numbers of white blood cells. For this reason one author says that women may well be the "firebreak" which stops the spread of AIDS among heterosexuals.(4)

C. WHY ARE HOMOSEXUALS AT RISK?

Experts have come to believe that the overwhelming risk factor with regard to the sexual spread of AIDS is receptive anal intercourse, a practice common among homosexuals. A recent study of 240 men who became infected with AIDS found that 236 of them had engaged in receptive anal intercourse.(4) Anal intercourse presents greater danger than vaginal intercourse for several reasons:

1) The rectum, unlike the vagina, is easily ruptured.

2) In the rectum, unlike the vagina, the blood supply is very close to the surface.

3) The vagina provides far more natural lubrication than the rectum.

4) Condoms are far more likely to fall off or tear during anal intercourse.

Other factors contributing to the greater likelihood of AIDS transmissions by homosexuals than by heterosexuals include:

1) Promiscuity - A 1981 CDC study of homosexual AIDS victims found that they had, on the average, 61 different partners a year.(4)

2) STD's - Homosexual males are 3 times as likely to get gonorrhea, and 14 times more likely to have had syphilis than heterosexuals. Hepatitis B, relatively uncommon among non-IV drug abusing heterosexuals, is epidemic among active homosexuals. (Hafer, 1986)(8)

3) "Fisting" - A practice among homosexuals which causes trauma to the rectum.

D. ADOLESCENTS, AIDS, AND IV DRUG ABUSE

The Majority report minimizes the danger of IV drug abuse as a means of spreading AIDS among heterosexual teens. In the discussion of minority teens, IV drug abuse is never mentioned. The section on IV drug abuse and adolescents covers less than one page and highlights testimony that the youths "most at risk for infection via shared needles are high school football players and other athletes who share needles for steroid injection."

Yet, as found by the Majority report, 23% of youth with AIDS in New York City are IV drug abusers and 11% are the female sexual partners of either drug abusers or bisexual men. The overwhelming majority of pediatric AIDS cases are those of babies born to women who are either IV drug abusers or sexual partners of IV drug abusers.

Heterosexuals are in danger from AIDS, but not primarily through sexual activity. The extent to which AIDS spreads among heterosexuals is due almost entirely to the behavior of IV drug abusers. Pauline Ann Thomas, the epidemologist in charge of NYC's AIDS surveillance program, explained:

> In New York City, which has the highest number of heterosexual cases, the statistics do not show significant heterosexual spread through sexual contact, but rather through primarily poorer people's use of IV drugs...It's not a case of the middle-class johns of prostitutes taking it back to their wives in the suburbs. Heterosexual spread is a drug problem--period. (6)

Dr. Robert C Gallo, the National Cancer Institute researcher who was the co-discoverer of the AIDS virus, says:

> There's no doubt in my mind we should be focusing on the high-risk groups, particularly the addict problem. That and Africa make everything else seem trivial by comparison. The drug problem is a mess. It's a national and international disgrace of the first order.(6)

Finally, Surgeon General Koop explains:

> ...The bottom line is that if you are going to contain AIDS in the United States, you've got to contain intravenous drug abuse.(11)

E. AIDS, ADOLESCENTS, AND THE PROMISE OF SAFE(R) SEX

> An AIDS education that accepts children's sexual activity as inevitable and focuses only on 'safe sex' will be at best ineffectual, at worst itself a cause of serious harm. Young people should be taught that the best precaution is abstinence until it is possible to establish a mutually faithful monogamous relationship. (William J. Bennett, Secretary of Education; C. Everett Koop, Surgeon General, January 30, 1987)

The Majority report quotes the same statistic five times- that 70% of the girls have engaged in sexual intercourse at least once by age 20. It is as if repeating this fact enough times makes it irreversible, or at least indisputable. According to the 1982 National Survey of Family Growth, 42% of all 15-19 year old unmarried women had experienced sexual intercourse.

It is clear that a minority of school-age girls, regardless of which survey you prefer, have engaged in sexual intercourse. The presumption of inevitability is a key assumption if you dismiss as irrelevant, as the Majority has, the option of teaching responsibility, character and the importance of sexual activity being confined to inside marriage.

Condoms and AIDS

On September 21, 1987, Surgeon General Koop issued a warning that prophylactics have "extraordinarily high" failure rates among homosexuals. The same warning, he explained, applies to heterosexuals who practice anal intercourse.(12) In an interview a few days earlier, the Surgeon General explained why condoms fail more often in anal intercourse.(13)

> That's entirely different. The rectum was not made for intercourse. It's at the wrong angle, it's the wrong size, it doesn't have the same kind of tough lining that the vagina does. It has its blood supply directly under the mucosa. Therefore, you would expect a great many more failures of condoms in rectal intercourse than you would in vaginal intercourse, and it's important to know that.

The Surgeon General has explained that since writing his report on AIDS which recommends condom use for both homosexuals and heterosexuals, he has been "surprised" to find an almost complete lack of research on condom failure rates and causes.(12)

Several recent studies show very high condom failure rates for anal intercourse:

> Prostitutes reported condoms broke up to 50% of the time during anal intercourse, in a London study.(14)

> Condoms frequently ruptured and slipped off in a Netherlands study of 17 homosexual couples engaging in 200 acts of anal intercourse with condoms.(15)

> -One brand of condom slipped off at the rate of 33%.

-One brand of condom's rupture rate was 22%, another was 20%.

-Overall, the condoms had a rupture rate of 11% and a slippage rate of 15%.

-The types of condoms which offered the best protection were least likely to be used. "The stiffest condoms seemed to be safer than the others, but they were also the least liked and therefore unacceptable to the participants."

Condom-failure is not a problem for homosexuals only. In a study conducted by Dr. Margaret Fischl at the University of Miami, 17% of uninfected wives of infected men became infected themselves. (16) Dr. Fischl commented:

> Although condom use appeared to decrease the rate of HIV tranmission, seroconversion occurred.
>
> These data suggest that condom use may not afford complete protection against the heterosexual transmission of AIDS.

Condoms have long been used as a contraceptive among heterosexuals. According to the 1982 National Survey of Family Growth, 11% of single women and 14% of married women who use condoms for contraception have unplanned pregnancies in the first year of use. The failure to prevent pregnancy by condom use is especially significant because a woman is fertile for only a few days each month. In addition, the AIDS virus is one five hundreth the size of a sperm cell, as Dr. Wayne Lutton told the Select Committee (June 18th hearing). Thus, the more porous condoms might allow transmission even without breaking or slipping. The Surgeon General has warned previously that condoms made of lamb membrane material (popular among homosexuals because they resist tearing) do not block

the AIDS virus.(12)

Dr. Malcom Potts, one of the inventors of prophylactics lubricated with spermicides, explains:

> We cannot tell people how much protection condoms give....I'm always amazed that we know the atomic structure of the AIDS virus but don't know much about condoms.(17)

Dr. Bruce Voeller, president of the Mariposa Foundation, which is conducting research on effectiveness and durability of condoms, warns:

> The safe-sex message just isn't true... You're still playing a kind of Russian roulette. Instead of having six bullets in the chamber, you have one. (17)

In January, 1987, NIH announced that it will fund a study of the effectiveness of condoms and spermicide in preventing AIDS transmission under real life conditions.(18) The condom industry, however, has launched an intensive campaign to weaken this study by insisting upon less rigorous tests and standards. (19)

Beyond the problem of condom failure among both homosexuals and heterosexuals lies the more difficult issue of human failure. A significant percentage of "condom failures" have in fact been a matter of human failure. Moreover, there is strong evidence that these human failures will occur more often among adolescents than among the population at large. For example, single women under 18 who use condoms to prevent pregnancy have an 18% failure rate in the first year of use; 18-19 year olds have a 16% failure rate; 20-24 year olds have a 12% rate. By contrast, single women aged 30-44 have a 3% failure rate.(20)

Surgeon General Koop's recent letter to the Journal of the American Medical Association (JAMA) contains some advice which could provide the basis for a legislative initiative. Koop told the nation's doctors, for the first time, that anal intercourse "is simply too dangerous a practice." His statement was so strongly worded, in fact, some variation of it should appear as a "Surgeon General's warning" on every condom sold in this country. Koop said:

> Do not practice anal intercourse; the rectal mucosa bleeds easily and provides an entry for HIV. Condoms provide some protection, but anal intercourse is simply too dangerous a practice.

F. AIDS EDUCATION: HOW EFFECTIVE IS IT?

A survey of University of Maryland students found that though 95% of students knew about AIDS prevention, most of them did not change their behavior.(21)

> -Of students practicing anal sex, 68% said they made no change, and only 27% said they practiced it less frequently.
>
> -Of students having sex with prostitutes, 56% made no change, and only 37% did so less frequently.
>
> -Of students sharing needles, 76% made no change, and only 14% did so less frequently.

Researchers for the study concluded:

> We found that knowledge is reasonably high, yet there is little personalization of risk or behavior change due to AIDS.

These results are compatible with those of similar studies across the country and around the world.

A review of four studies conducted at U.S. universities

concluded:(22)

> The collective results revealed that the majority of students are reasonably knowledgeable about the transmission of the AIDS virus and proper preventive measures. Unfortunately, only a minority are translating their knowledge into behavioral change.

A study of 303 homosexual men in northeast Ohio stated:(23)

> We have concluded that educational efforts on safe sex education in our area have resulted in clinically meaningful behavior modification in only a small segment of the socially and sexually active homosexual community.

The study found that only 28% practiced totally safe sex. 71% persisted in some activities that have been clearly described as unsafe. Three fourths of the persons participating in unsafe activities nevertheless felt comfortable that they had taken adequate precautions.

A study of the massive AIDS educational effort in Britain concluded:(24)

> "The campaigns had no effect on changing sexual behavior," despite a "significant knowledge gain."

Dr. Vernon Mark, of the Harvard Medical School, summarized the failure of public education regarding condom use in his testimony before the Select Committee in June, 1987:

> The futility of educating the public to use condoms as the primary tool to contain the HIV epidemic was revealed at the recent Washington, DC conference on AIDS. This was illustrated in two studies of gay men - a group supposedly most educable to changing their sexual behavior. In one, a national study conducted on 4,955 gay men in 1984 showed that the use of condoms doubled over the course of the first four visits to the study center. However, over 66% of the 2500 men who still engaged in anal sex did not use condoms and 44% used nitrite inhalants to enhance their sexual pleasure (which further

contributes to user failure and irresponsibility). A second study of 503 gay and bisexual men done in 1986 showed that 91% were aware that anal receptive sex was the most risky sexual practice and 90% knew that condoms could reduce the spread of AIDS. Yet, 62% stated that they never or hardly ever used a condom in insertive anal sex and 64% said that their partners were guilty of the same dangerous behavior. Thirty-five percent of them were high on alcohol or recreational drugs during sexual intercourse and this may have contributed to the lack of condom usage. Nor was the American gay community the only group to continue indulging in unsafe sex practices. The British have reported very little change in high risk sexual intercourse even after a massive national educational campaign to promote the use of condoms. And American researchers treating hemophiliacs infected with HIV agreed that a lack of compliance in using condoms was their chief concern about otherwise pristine sexual practices in this largely monagomous cohort of AIDS patients.

G. SAFE SEX IN SCHOOL

> Telling a person who engages in high-risk behavior to use a condom "is like telling someone who is driving drunk to use a seat belt."(17) (Malcolm Potts, President, Family Health Initiative)

According to Surgeon General Koop, information gathered during the winter of 1986 showed that 40 of the nation's 73 largest school districts were providing education about AIDS, and 24 of the remaining 33 districts were planning such education. Seventeen states and the District of Columbia require AIDS instruction in schools. Those courses usually begin in the seventh grade.(26) At least five dozen videos have been produced for elementary and high school use, and they are aggressively marketed. Helen Todd, film and video supervisor for the Memphis, TN, school system says, "I'm constantly sending back videos." She has already bought five.(26)

The big question, not treated in the Majority report, is, 'What do these AIDS education programs teach?" Though most texts, programs, and videos mention abstinence as an option, few promote it with real conviction or effectiveness. For example, one widely used teachers guide is Teaching AIDS: A Resource Guide on Acquired Immune

Deficiency Syndrome, written by Marcia Quackenbush (quoted in the Majority report) and Pamela Sargent. This text never specifically recommends abstinence as the best and most effective way for an adolescent to avoid AIDS. In a chapter on teaching plans, a section addresses 'How can we help change people's beliefs and behaviors about safe sex?", and gives this advice (p. 33):

1. Educate everyone about safe sex.

2. Educate everyone about condom use, including how and where to get them, how to use them, how to talk about condom use with partners.

3. Tell young people about family planning or health clinics where they can get condoms for free or at cost.

4. Educate about how to make condom use part of the intimate sharing of sexuality.

5. Educate sexually active youth to always have condoms available in situations where they might need them, so that spontaneity is not affected.

6. Others?

A recent report by the Center for Population Options (CPO), a promoter of school-based clinics, suggests these ways to promote condom use among teens:(27)

-Encourage adolescents to carry condoms routinely to help out friends or be prepared themselves for situations where "it just happened."

-Assign homework such as purchasing condoms at a pharmacy. "In some schools, students can't pass their health class without buying a condom," says the report.

-Ask students to submit two-line verses to a "condom couplet contest."

A representative of the CPO, admitting that some of these suggestions may sound "surprising" contends that the U.S. lags behind much of the world in providing explicit information about condoms.

> In Thailand, school children make a game of blowing up condoms like balloons and at the same time get used to handling and talking about condoms...In Hong Kong and Mexico, clear plastic key rings that encase a condom are distributed to teens. They read, "In case of emergency, break glass."

The Solution

> Teenagers' beliefs and convictions about proper sexual behavior are more effective in shaping their behavior than mere knowledge about devices such as condoms. Indeed, promoting the use of condoms can suggest to teenagers that adults expect them to engage in sexual intercourse. This danger must be borne in mind in any discussion. (AIDS and the Education of Our Children, U.S. Department of Education)

"Safe sex" is not a new concept among adolescents. For at least a decade and a half, federal, state, and local governments and schools have been teaching teens about safe sex. Unfortunately, their efforts failed. Teens were told that contraceptives would keep them safe from pregnancy but their pregnancy rate has skyrocketed. So has their rate of sexually transmitted diseases.

In 1971, 3 out of 10 unmarried sexually active teenage* girls had become pregnant. Over the next decade contraceptive use by these teens increased dramatically. But in 1976, 1979 and 1982 (all the years that surveys were taken) still 3 out of 10 of these teens had become pregnant. During the 11 year span from 1971 to 1982, the percentage of all unmarried teenage girls who had become pregnant increased over 50%. Why? Because during that same period, the percentage of unmarried teenage girls who were sexually active also increased by more than 50%.(28)

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* 15-19 years old

There are two basic variables which affect adolescent pregnancy:

1) the percentage of unmarried teenage girls who are sexually active,
2) the percentage of the above group who get pregnant.

Almost two decades ago many government officials and educators decided that it would be futile to try to prevent teenagers from becoming sexually active. Therefore, efforts to reduce teen pregnancy began to focus exclusively on encouraging sexually active teens to use contraceptives. These teens did use contraceptives, but did not use them very well. Their pregnancy rate hardly budged. All efforts to affect the second variable came to nought. In the meantime the percentage of those who were sexually active grew by more than half. Consequently, the percentage of all unmarried teens who had become pregnant also grew by more than half. In the end, the variable which no one thought could be changed was the variable which made the difference. Unfortunately, the difference was in the wrong direction.

Government officials and educators have learned a lesson from this experience; but some have learned more than others. And some, no doubt, understood the lesson all along.

A new AIDS prevention campaign announced in November, 1987, by Mayor Edward I. Koch of New York City advises teenagers that the best way to avoid AIDS is by saying no to sex. The campaign is a 180-degree turn-around from the city's first ads introduced in the previous spring. These ads, which encouraged women to carry condoms, were rejected by most local commercial stations. Koch explained that the new ads stress abstinence because of the belief by many that the use of condoms or any kind of sex outside of marriage is morally wrong. "It is not a kook position. Now we have

to address that." (29)

Very few of the new "safe sex" texts, videos, and other learning tools omit some mention of abstinence. But all too often the mention of abstinence as an "option" amounts to little more than lip service.

Secretary of Education William J. Bennett, is a strong advocate of programs which clearly promote abstinence among unmarried teens and help teens to achieve that goal. In addition, the Department of Education booklet, AIDS and the Education of Our Children clearly states that AIDS education within the schools must be locally determined and should:

* Be provided with the consent and involvement of parents.
* Uphold monogamy in marriage as desireable and worthy.
* Assist children in developing character with clear standards of right and wrong.
* Use materials which are appropriate to the age and development of the child.

The assumption that teenagers are inevitably sexually active is incorrect. Teenagers want adults to explain to them on how to resist the social and peer pressures that result in dangerous behavior.

* Many young people want to say "no" to sexual activity.

  - Nine out of ten girls under 16 wanted to learn how to say "no" to sexual activity, according to a study conducted by Atlanta's Grady Memorial Hospital.

- The 18th Annual Survey of High Achievers, compiled by Who's Who Among American High School Students, found that 73% of the students said that they never had sexual intercourse and 61% believed that sex should not be expected in a premarital romantic relationship. All the students surveyed boast A or B academic averages.

* Educational programs that emphasize responsibility teach young people to restrain their sexual behavior.

- The Community of Caring programs, sponsored by the Joseph P. Kennedy Foundation, teach sexuality in a context of moral, ethical, and family values. The Joseph P. Kennedy, Jr. Foundation established a network of Community of caring programs 11 years ago to help combat the problems of adolesent sexual activity and teen pregnancy. The program orginally focused on helping pregnant teenagers have healthy babies, but has expanded into other areas of concern - especially pregnancy prevention. A new curriculum, "Growing Up Caring" has recently been implemented in five school systems. The curriculum is based on the belief that teenagers become sexually active because they have not perceived their sexuality in a moral context. The program operates on the premise that any time sex education is taught, it must be taught within the context of the family and ethical values.
"Growing Up Caring" contains a section dealing with AIDS in its teaching units for teachers, parents, and other instructional personnel. Its discussions and activities emphasize morality and responsibility. For example, in the section on drug abuse, a point is made that teenagers are responsible not only for their health now but also for

their ability to become productive citizens and to establish strong and healthy families of their own. "Growing Up Caring" has recently been implemented in five school systems, and they report only 3% repeat pregnancies after twelve months, as opposed to a 15% national average reported by the Allen Guttmacher Institute.

- "Postponing Sexual Involvement" is an Atlanta program which helps adolescents "resist pressures to become sexually active." "Postponing Sexual Involvment" is a "How to Say No" program targeted to 13-to-15 year olds and their parents. The program is taught in Atlanta schools and is being implemented thoughout Georgia. The program was developed to help adolescents resist pressures to become sexually active. It consists of a series of four one hour sessions and a follow-up session. "Postponing Sexual Involvement" does not simply present information but gives teenagers the tools and skills they need to handle the reality of their sexuality. It also identifies the sources of societal pressures that are often responsible for early sexual activity. Parents receive a shortened version of the lessons. 70% of students taking the course said it taught them adolescents can postpone sexual activity without losing their friends respect.

- "Sex Respect" teaches young people to value their sexuality more highly and to postpone sexual activity until marriage. The U.S. Department of Health and Human Services reports in its assessment of the program: "positive and encouraging changes in attitudes towards sexual behavior, including the ability to control sexual desire."

- "Suddenly Sex Has Become Very Dangerous" (by Gooday Video of Quero, Texas) stresses abstinence as the only sure means of avoiding AIDS. Its distributors report it has been adopted in over 1000 school districts, and has been highly praised by the Arizona Department of Education, the Virginia Department of Education, and local school districts throughout.

- "Responsible for Myself" is a San Marcos, California program that teaches young people how to study, how to make decisions based on values, and that "abstinence is the only way for teenagers to deal with sex." Believing that today's young people need to learn about responsibility rather than learning by chance, at San Marcos Junior High School (San Marcos California), the staff, parents and community members put togther a program to encourage students to be responsible for themselves. Focusing on specific teenage problems such as sexual activity,drug use, poor self esteem, and poor study habits and decision-making skills, the planning group designed a program titled "Decision Making-Keys to Total Success." The section of the program entitled "Sexuality, Commitment, and Family" teaches children that abstinence is the only sensible way for teens to deal with sex. It seeks to instill appreciation for the creation of life, people. Negative peer pressure and media influnce are also discussed. The program helped reduce adolescent pregnancies significantly-from 147 in school year 1984-85 to 20 in school year 1986-87.

* Positive influences can reduce sexual activity rates.

- When adolescents and their parents hold values which stress responsibility, the teenagers' chances of having children out of wedlock are "significantly" reduced, according to an analysis of the 'High School and Beyond Survey."

- Alfred Kinsey in Sexual Behavior in the Human Male shows a positive correlation between greater church activity (or greater devoutness) and greater abstention from non-marital intercourse.

- Strong religious convictions influence many teenagers to avoid sexual activity. (Several studies have found that young women 15-19 who said religion was important to them and went to church were less likely to report having had sexual intercourse)

- A close mother-daughter relationship reduces the likelihood of premarital sexual activity by the daughter.

- Teenage girls who grow up in households with both male and female parents are less likely to be sexually active.

- Certain educational programs stressing character and moral restraint report success in affecting attitudes and behavior. (See section below.)

* Sexual activity rates can decline as well as increase.

- The percentage of children who have had sexual intercourse is dropping for some teens and leveling off for others (e.g., the proportion of black adolescent girls who were sexually active declined from 65% in 1979 to 53% in 1982

after increasing from 51% in 1971 to 64% in 1976).

* Most teenagers are not having sexual intercourse.

  - For example, the majority of girls aged 15-19 have never had sexual intercourse, though the number of girls in this age group who are sexually active increased from 28% between 1971 and 1982.

The Logic of Abstinence for Teens

We have demonstrated thus far that AIDS education and condom education have failed, that some alternative programs have indeed worked, and there are other influences on teens that can positively influence them as well. What follows is yet another argument for promoting what is always agreed is the most effective alternative for kids: the logical argument.

1) Teens are risk-takers.

The Majority report notes that adolescence is a period "characterized by a sense of invulnerability" (pg 27). In other words, teenagers routinely accept physical risks that others reject.

Beatrix A. Hamburg, a child psychiatrist at Mount Sinai Hospital in New York City, told The New York Times recently that around age 10 youngsters "enter a risky period when they do lots of exploring at a time when their cognitive development has not yet reached the point where they can make judgments that will keep them out of trouble. They

cannot really comprehend laws of probability. And they also have ideas of invulnerability that permeate them that they can safely take a known risk." These influences seem to peak, the Times article said, in the years between 10 and the mid-20s. (NY Times, 11-24-87)

2) Risk-takers will not alter their behavior unless they receive an unequivocal message to do so.

Our society has concluded that the most effective way to reach those who knowingly endanger themselves though high risk behavior - whether it be consumption of drugs, alcohol, fatty foods, or tobacco - is through a message of abstinence. Alcoholics Anonymous (AA) tells its members to "just say no" to alcohol: drug counselors tell drug addicts to "just say no" to drugs; heart and lung specialists tell their patients to "just say no" to cigarettes and fatty foods. But when it comes to AIDS, there are those who advocate an ambiguous message that amounts to: engage in sex, but be careful. Several years ago, a medical journal published a study which recommended that alcoholics be allowed an occasional drink. AA and other concerned groups angrily disputed the findings, arguing in essence that the only way to cure an alcoholic is through total abstinence.

As the Surgeon General has pointed out, only 3.0% of sexually active teenagers in a Massachsetts study used contraceptive devices effectively.(page 39) Teenagers simply will not heed the mixed message favored by some ("go ahead and have sex, but be sure to use a latex condom supplemented with jelly or cream containing at least 65mg of nonoxynol-9"). If Dr. Hein is correct that teenagers

tend to focus on "concrete" rather than "abstract" thinking and "tangible" rather than "long-term" factors, then the Majority's style of AIDS education, which is itself abstract and confused, is misguided.

(3) Sexual abstinence makes sense for teenagers.

Contrary to the assertions in the Majority report, abstinence is a reasonable message to impart to teenagers because most teenagers are sexually innocent.

By age 15, an age at which many teenagers have already begun sex education classes, over 80% of the boys and 90% of the girls have not engaged in sexual intercourse. Even two years later, at age 17, the vast majority of girls and a slight majority of boys are virgins. Clearly, to assume that all 15 year olds are sexual sophisticates and structure AIDS education courses around this false premise, is to mislead and possibly harm many innocent children.

III. THE NATIONWIDE PICTURE

A. THE FEDERAL SHARE

The Majority report fails to yield a comprehensive picture of (1) how much federal money is now going for AIDS related research; (2) how much federal money is estimated for FY88 such research; (3) the extent of a state's ability to contribute its own funds to complement the federal war on AIDS.

It should be noted that every year Congress has dramatically increased money for AIDS related research. "In each fiscal year since 1983, the Congress has increased the AIDS budget by 76% to 115% over the previous year." (GAO, 1987, p. 14) Recent estimates by the Government Accounting Office (August, 1987) show "federal spending for AIDS across all programs, including Medicaid and Medicare outlays and Social Security payments, will total nearly $1.3 billion for FY 1988." (Intergovernmental Health Policy Project, GWU, 1987)

An examination of the table below shows the dramatic increase in AIDS related research from just the Public Health Service alone.

Table 1 : PHS Expenditures/Budgets for AIDS, Fiscal Years 1981-1988.

Dollars in thousands

Year	Amount
1981 (Actual)	$ 200
1982 (Actual)	5,555
1983 (Actual)	28,736
1984 (Actual)	61,460
1985 (Actual)	108,618
1986 (Actual)	233,812
1987 (Estimate)	447,375
1988 (Proposed)	790,661

Source: U.S. Congressional Research Service, Federal Funding for AIDS Research, Washington, D.C. (Feb.2, 1987), p.9 and HHS.

According to the Office of Management and Budget, the federal expenditures for AIDS have steadily evolved: in fiscal year 1986, $436 million dollars went to AIDS related research; in fiscal year 1987 estimates are as high as $839 million; and in fiscal year 1988 the estimate is $1,322,000,000. These figures include all AIDS related monies appropriated for the Public Health Service, the federal share of Medicaid, the departments of Defense and Labor, the Social Security Administration and the Veterans Administration. The breakdown of these figures show FY87 and FY88 dollars:

Federal Expenditures for AIDS, Fiscal Years 1987-1988
(dollars in millions)

Program or Department	1987 Amount	1988(estimated)
Public Health Service	$494	791
Medicaid	210	375
Social Security	26	48
Veterans Administration	30	44
Department of Defense	74	52
Department of Labor	1	1
Department of Justice	3	6
Department of State	1	5

Source: U.S. Congressional Research Service, Washington D.C. Dec. 8, 1987.

B. THE STATE SHARE

It is impossible to get a nationwide picture of current resources going to AIDS related research without looking at state expenditures: "Since fiscal 1983-84, states have allocated more than $239 million in general revenues to AIDS activities -- starting at $9.3 million in fiscal year 1983-84, increasing to $27.5 million in 1985-86, and reaching $126.3 million by 1987-88." (Intergovernmental Health Policy Project, GWU, 1987, p. 2)

These numbers do not include state spending through Medicaid. "In addition to the $126.3 million states have reported allocating to AIDS

in fiscal 1987-88, the federal Health Care Financing Administration (HCFA) estimates the states will spend $300 million through Medicaid for the direct medical care expenses of AIDS patients." (Intergovernmental Health Policy Project, GWU, 1987, p. 2)

What Are State Funding Priorities?

States appear more willing to appropriate state dollars for education and information programs and administrative activities related to AIDS related programs. In addition, states are supplementing federal grant funds to support counseling and testing programs and to develop direct patient care programs.

There is an increasing demand for testing and counseling services at the state level and states appear to be putting more of their money into testing than in previous years. 'More than half of the states reporting AIDS expenditures are allocating funds to expand testing and counseling services." (Intergovernmental Health Policy Project, GWU, 1987, p. 3)

All States Are Responding to the Threat of the AIDS Epidemic, Even States With Low Incident Rates

It is clear in reviewing state-only, per-capita expenditures that the states with high incidence rates are spending more on a per-capita basis. 'However, the significant trend is that an increasing number of states, even those with relatively low incidence rates, are allocating funds in an attempt to manage the situation before it becomes a major public health problem within their own borders." (Intergovernmental Health Policy Project, GWU, 1987, p.5)

Conclusion

The public policy goals in combatting the AIDS epidemic are straightforward: to safeguard those who are not infected, to care for those who are infected, and to do everything that is humanly possible to save precious lives that are at risk for this deadly disease.

It is time to move beyond ideology and to break up this public policy stalemate. At the same time that we avoid hysteria, we must also avoid obscuring the facts about transmission. What we know about AIDS is sobering and it ought to trigger a more serious national response than what we have witnessed thus far. A stronger, more comprehensive national response means that federal, state, and local policymakers need to closely examine all the facts, weigh the expert opinions as well as the claims of advocacy groups in order to devise an effective, just and humane policy that promotes the common good.

We must integrate the ever changing factual evidence into appropriate policy initiatives. We must be open to objections and to criticisms but at the same time have the collective wisdom to know the difference between tolerance and moral relativism. We need to get on with the job of stopping the transmission of AIDS. We can do this with a firm clearheaded public policy aimed at a preventable disease.

Dan Coats, Ranking Minority Member
Frank Wolf
Barbara Vucanovich
Jack Kemp
Ron Packard
Beau Boulter
Denny Hastert
Clyde Holloway

FOOTNOTES

1. Thomas Starcher, Centers for Disease Control, personal communication, June 1987.

2. Thomas Starcher, Centers for Disease Control, personal communication, November 1987.

3. "AIDS Weekly Surveillance Reports," Centers for Disease Control, November 16, 1987.

4. Michael A. Fumento, "AIDS: Are Heterosexuals at Risk?" Commentary, November 1987.

5. "Human Immunodeficiency Virus Infections In the United States: A Review of Current Knowledge and Plans for Expansion of HIV Surveillance Activities," A Report to the Domestic Policy Council by the Department of Health and Human Services, Public Health Service and Centers for Disease Control, November 30, 1987.

6. "AIDS Threat To All - How Serious?," Los Angeles Times, August 14, 1987.

7. "AIDS Rate In L.A. Addicts 'Very Low,' Unlike N.Y.'s," Los Angeles Times, November 21, 1987.

8. Dick Hafer, Homosexuality: Legitimate Alternative Deathstyle, January 1986.

9. "Despite Risky Sex, Women Elude HIV," The Washington Times, August 14, 1987.

10. "Report Sees Drop In AIDS," Chicago Tribune, November 15, 1987.

11. Quoted by William Raspberry, "AIDS: Progress and New Concern," Chicago Tribune, November 2, 1987.

12. "Koop Warns On Risk of AIDS in Condom Use," Los Angeles Times, September 22, 1987.

13. "Inquiry--Topic: Fighting AIDS Panic," U.S.A. Today, September 18, 1987.

14. The Lancet, December 21/28, 1985, reporting on a survey of London prostitutes.

15. Lode Wigersma, Ron Oud, "Safety and acceptability of condoms for use by homosexual men as a prophylactic against transmission of HIV during anogenital sexual intercourse," British Medical Journal, July 11, 1987, p. 94.

16. Margaret A. Fischl, et. al., "Heterosexual Transmission of Human Immunodeficiency virus (HIV): Relationship of Sexual Practices to Serconversion," III International Conference on AIDS, June 1-5, 1987, Abstracts Volume, p. 178.

17. "Condoms: Experts Fear False Sense of Security," The New York Times, August 18, 1987.

18. "AIDS Study to Test Condoms, Spermicides," The Los Angeles Times, January 16, 1987.

19. "Condom Industry Seeking Limits on U.S. Study," The Los Angeles Times, August 28, 1987.

20. William Grady, Mark Hayward, Junichi Yagi, "Contraceptive Failure in the United States: Estimates from the 1982 National Survey of Family Growth," Family Planning Perspectives, September/October 1986, pp. 203,204.

21. "Students haven't changed behavior despite AIDS fear," The Washington Times, September 3, 1987; Vicki S. Freimuth, Timothy Edgar, Sharon L. Hammond, "College Students Awareness and Interpretation of the AIDS Risk," n.d. (to be published in Science, Technology and Human Values, December 1987).

22. Timothy Edgar, Vicki S. Freimuth, Sharon L. Hammond, "Communicating the Risk to College Students: The Problem of Motivating Change," n.d., p. 2 (to be published in Health Education Research: Theory and Practice, December 1987).

23. Leonard H. Calabrese, Buck Harris, Kirk Easley, "Analysis of Variables Impacting on Safe Sexual Behavior Among Homosexual Men in an Area of Low Incidence for AIDS," III International Conference on AIDS, Abstracts Volumes, p. 193.

24. Lorraine Sheer, John Green, "Evaluation of Health Education in Britian," III International Conference on AIDS, Abstracts Volume, p. 56. "Aggressive Prevention Efforts Proliferate," Washington Post, June 5, 1987.

25. "Schools Move Towards AIDS Education," U.S.A. Today, December 4, 1987.

26. "AIDS Videos for Schools," The Wall Street Journal, November 18, 1987.

27. "Adolescents At High Risk of AIDS, Group Says," Associated Press, November 6, 1987.

28. Teen Pregnancy: What is Being Done: A State-By-State Look, A Report of the Select Committee on Children, Youth and Familes, Minority Views, December 1986.

29. "New City Ads Urge: 'Say No to Sex,'" The New York Post, November 12, 1987.